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Using narratives to explore the role of gender-based violence and inequality on the reproductive health and disease status of HIV+ African immigrant women

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Using narratives to explore the role of gender-based violence and inequality on the reproductive health and disease status of HIV+ African immigrant women

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Dedication

To my mom for all her love and support. Thanks for always believing in me and having faith in my future.

To the women who so bravely participated in this study. I am touched by your strength, courage and resilience. I am honored to have met you.

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Using narratives to explore the role of gender-based violence and inequality on the reproductive health and disease status of HIV+ African immigrant women

Joy Allison Learman, PhD

The University of Texas at Austin, 2013

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The United Nations Population Fund has identified gender inequality and gender-based violence as two of the main threats to women's reproductive health. In fact, researchers have estimated that between one quarter and one half of all women with sexually transmitted infections, including HIV, have abusive partners. Given the pervasiveness and far-reaching effects of these phenomena, it is essential to take steps to mitigate the possible negative consequences on women's reproductive health, including HIV status. This exploratory qualitative research study was designed to gain further insight into the contextual factors and personal experiences of HIV positive African immigrant women, with the goal of informing the development of contextually-tailored HIV risk reduction strategies. This study, guided by a theoretical framework based on Feminist Theory, Critical Race Theory and the Theory of Gender and Power, utilized in-depth interviews with six HIV positive African immigrant women. Narrative analysis was used to explore the women's narratives on the role of gender-based violence and

inequality on their disease status. The main overarching theme revealed in the women's narratives was that marriage is a vulnerable status that can actually put women at risk for contracting HIV. This vulnerability is based on social norms that state once women are married, they: 1) should *not* say "No" to sex with their husbands, 2) should *not* ask their husbands to use a condom, and 3) should *not* divorce husbands for having concurrent sexual partners. The women's narratives showed how the gender norms and decision-making process they observed in their families of origin, and in the larger community, affect their sexual decision making in their intimate relationships. Their narratives also introduced us to their experiences of sexual, physical and emotional abuse, as well as physical and emotional neglect. Finally, listening to the narratives of HIV positive African immigrant women educated us on the stigma and silence around HIV in their community, in addition to paving the way for recommendations on preventing the spread of HIV in their communities in the United States, as well as abroad. Implications for social work practice and policy, as well as future research are discussed.

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Chapter One: Introduction

This dissertation is an exploratory qualitative study designed to gain further insight into the contextual factors and personal experiences of HIV positive (HIV+) Black African immigrant women with the goal of identifying potential means of reducing the spread of HIV. Using a sample of African immigrant women, this study sought to uncover how gender-based violence, gender inequality and contextual factors, such as poverty and migration, affect women's vulnerability for HIV infection. This study fills a significant gap in the scholarly literature, as it (a) emphasizes the experiences of an understudied population of HIV + African immigrant women, (b) uses narrative analysis to identify how complex phenomena such as gender-based violence and gender inequality relate to women's health, and (c) informs the development of HIV/AIDS risk reduction interventions designed to meet the unique needs of this underserved population.

This chapter introduces the scholarship in the area of gender-based violence and gender inequality and their role in women's reproductive health and disease status. Although the scholarly literature on reproductive health often focuses on contraception and pregnancy (see Gazmararian, Petersen, Spitz, Goodwin, Saltzman, & Marks, 2000), reproductive health includes information on testing and treatment for sexually transmitted infections (STIs) and HIV (World Youth Alliance, 2012). For the purpose of this study, reproductive health is conceptualized broadly with a focus on HIV infection.

PROBLEM STATEMENT

The United Nations Population Fund (UNFPA) has identified gender-based violence and gender inequality as two of the main threats to women's reproductive health

(UNFPA, 2010). In fact, researchers have estimated that between one quarter and one half of all women with STIs, including HIV, have abusive partners (Champion & Shain, 1998). These findings are supported by the World Health Organization (WHO) which reported that "…women living with HIV are more likely to have experienced violence and woman who have experienced violence are more likely to have HIV" (WHO, 2010, p. 2). Gender-based violence puts women at risk for contracting HIV because perpetrators seek to control their partner's behavior, thus reducing their sexual autonomy and decision-making (Wingood & DiClemente, 1998). Perpetrators may also engage in reproductive coercion (Coggins & Bullock, 2003; Miller, et al., 2010), as well as acts of sexual violence and coercion that put women at direct risk for contracting STIs, including HIV (McFarlane, et al., 2005). Gender inequality enhances women's risk by promoting rigid gender norms, especially in terms of sexuality (UNFPA, 2010).

Women's risk for experiencing these phenomena is exacerbated by contextual factors, such as poverty (Jewkes, et al., 2002) and migration (Benjamin & Murchison, 2004). These contextual factors also place women at an increased risk for contracting HIV (Benjamin & Murchison, 2004; Westhoff, et al., 2008). Thus, immigrant women face heightened risk levels mainly because the migration process itself makes women vulnerable to experiencing gender-based violence, including rape, and inequality (Adanu & Johnson, 2009). Unfortunately, there is a dearth of research on the experiences of immigrant women (Berman, Giron & Marroquin, 2006).

Research into the HIV-related experiences of immigrant women from sub-Saharan Africa is essential as women of African descent are disproportionately affected by HIV

both in the United States and worldwide (Campbell, Baty Lucea, Stockman, & Draughon, 2013). Although participation in this study was open to African women of any racial and/or ethnic descent, the sample recruited for this study was comprised of Black African women who migrated to the United States. The term African immigrant women or African-born women is used in this study in order to be clear that the sample does not include African American women, or American-born women of African descent.

Sub-Saharan Africa is the region most deeply impacted by the HIV/AIDS epidemic; with over 60% of HIV+ individuals (25.8 million) in the world (United Nations General Assembly, 2001). It should be noted here that the term sub-Saharan Africa is commonly used in international research. Nonetheless, the validity of the term is increasingly coming into question. In general, it is used to refer to all African nations except those in North Africa, including Algeria, Egypt, Libya, Morocco, Tunisia, and Western Sahara, as well as the Sudan in East Africa. Ekwe-Ekwe (2012) argues in Pambazuka, a news forum created by Fahamu, an organization working to support the movement for social justice in Africa, that it is a Euro-centric racist geopolitical term. It is maintained that the term is an artificial concept to distinguish Arab-led countries from those that are African-led. This is evidenced by the fact that the Sudan is excluded even though Black Africans make up the majority of its population. Furthermore, it is argued that the use of the derogatory prefix "sub" also has racist connotations and may be used to identify social issues, such as HIV, as "Black" issues (Ekwe-Ekwe, 2012). While recognizing the problematic nature of the term, it has been used here in keeping with its

conventional use in most of the international research on HIV/AIDS. However, it is hoped that more African-centric language will be used in future research.

African women carry a heavy burden due to disproportionate infection rates (Dunkle, et al., 2004). This heavy burden is also felt by African-born women living in the United States. It is estimated that approximately four out of ten newly diagnosed women in metropolitan areas of the United States are African-born (Kerani, et al., 2008). Our failure to effectively support these women and, thus, inability to address reproductive health issues, will have major repercussions for women, as well as public health and even the global economy (Alzate, 2009).

Given the pervasiveness and far-reaching effects of gender-based violence and inequality, it is essential to take steps to mitigate the possible negative consequences these phenomena can have on women's reproductive health, including HIV status. In so doing, it is imperative to recognize that women are not always in a position to make healthy, well-informed decisions in terms of their sexual and reproductive health (Amaro, et al., 2001). Therefore, we must utilize contextualized approaches which acknowledge the impact of constrained decision-making on women's choices, as well as recognize the diversity of women and their sexual experiences (Amaro, et al., 2001).

CONTEXTUAL NATURE OF WOMEN'S SEXUALITY

It is essential to have a clear understanding of how the terms gender-based violence and gender inequality were conceptualized for the purpose of this study. Gender is a socially constructed concept of biological sex which uses social and cultural norms to polarize ideals of femininity and masculinity; this difference is then used to support

structural inequalities (Wingwood & DiClemente, 2000). For example, gender has been socially constructed in such a way that women are socialized that to be feminine means to be docile and submissive. Men have been socialized that to be masculine means to be dominant and aggressive. Thus, it should be noted that gender-based violence and gender inequality are broadly defined to include the violence and inequality faced by individuals who do not fit into the narrowly prescribed definitions of femininity and masculinity, such as members of the LGBTQ community (O'Toole, Schiffman & Kiter Edwards, 2007). Moreover, "gender non-conforming individuals and sexual non-conforming individuals (i.e., lesbian, gay, bisexual, queer) are especially vulnerable to different expressions of gender-based violence", as well as gender inequality (González-López, personal communication**,** August 1, 2013). It is important to recognize that these forms of domination perpetrated by a patriarchal society are interrelated and are based upon the same principles (O'Toole, et al., 2007). However, due to the scope of this study, the terms gender-based violence and gender inequality are used to discuss issues related to women. Hence, in this study, gender-based violence is used interchangeably with the term violence against women and gender inequality refers to inequality experienced by women in a patriarchal society. Chapter Three defines each of these concepts in greater detail.

Gender-based Violence

Gender-based violence is a phenomenon found throughout the world. A large portion of the violence committed against women is perpetrated by their intimate partners. According to the World Health Organization's *Multi-country Study on Women's Health and Domestic Violence*, it is estimated that between approximately 10% to 60% of

ever married women have experienced physical intimate partner violence during their lifetimes (Garcia-Moreno, Jansen, Ellsberg, Heise & Watts, 2006). Over the course of their lifetime as many as one quarter of the women in some nations are raped in their intimate relationship (Jewkes, Sen, & Garcia-Moreno, 2002). Research has also shown that women who experience intimate partner violence suffer negative health outcomes, such as physical ailments (Campbell, 2002; Ullman & Brecklin, 2003), mental health issues (Bonomi, Andersen, Rivara & Thompson, 2007), and substance use disorders (El-Bassel, Gilbert, Schilling, & Wada, 2000), as well as reproductive disorders (Golding, 1996; McFarlane, et al., 2005).

The power and control exercised by men against women creates substantial barriers for women to make informed sexual decisions free from coercion about contraceptives and the successful negotiation of their use (Wingood & DiClemente, 1998). Women's histories of both physical and sexual violence are associated with increased STI rates (Martin, et al., 1999). In one study, researchers found that abused women were five times more likely to contract a STI (El-Bassel, et al., 1998), while another study found that women with a history of sexual assault were overrepresented among individuals diagnosed HIV+ (Brady, Gallagher, Berger, & Vega, 2002). Furthermore, male-controlled sexual decision-making, male perpetrated violence, and women's histories of sexual assault place women at increased risk for contracting the disease (Amaro, Raj & Reed, 2001).

Gender Inequality

Gender inequality is also a pervasive phenomenon based on the patriarchal oppression of women that affects the health and well-being of women internationally. In fact, women's overall health and risk for contracting STIs, including HIV, has been associated with gender inequality in the literature. As Amaro (2001) states, it is essential to consider the contextual nature of human sexuality as women's lower social status jeopardizes their reproductive health. Rigid customs designed to control women's sexuality (UNFPA, 2010) put women at further risk. For example, women in many cultures are taught to be sexually submissive to their husbands. Moreover, women deprived of economic opportunity may resort to marrying older, wealthier and more sexually experienced men in order to provide for their children financially. These scenarios, among endless others, endanger women's reproductive health and put them at risk for contracting STIs. On the other hand, it should be noted that some women without access to education and paid employment are able to successfully use marriage as a means of survival.

Many women also face additional contextual factors that put them at risk. In a review of public health level HIV risk reduction interventions, Wingwood and DiClemente (2000) found that socioeconomic factors, such as being a woman of color, being young (i.e., less than 20), living in poverty, and having a lack of education (i.e., less than a high school diploma) and employment (i.e., being unemployed or underemployed) increase HIV infection rates. Moreover, factors such as poverty can leave women particularly vulnerable to sexual violence. The relationship between poverty and sexual

violence is mediated through family stressors (Jewkes, 2002). In addition to financial stress, families living in poverty are more likely to have adult male members who undergo a crisis of masculinity due to expectations regarding their ability to provide for their family financially. These families are also more likely to have women who defy traditional gender roles (such as staying at home to care for children) in order to provide for their family themselves. In these situations, perpetrators may use violence as a means of establishing their role as the head of the family (Jewkes, 2002).

The *World Health Report on Violence* asserts that poverty also puts women at risk for sexual exploitation, coercion, engagement in survival sex (Jewkes, et al., 2002), as well as forced prostitution (Wiest, Mocellin, & Motsisi, 1994) in an effort to support themselves and/or their children. In order to feed their families, low-income women may find themselves at the mercy of educators and/or employers, putting them in a situation of constrained choices, vulnerable to threat, coercion and violence (Jewkes, et al., 2002). Thus, these contextual factors, which make women vulnerable to experiencing gender-based violence and sexual violence (Tjaden & Thoennes, 2000), virtually compound their HIV risk levels.

International Migration

Migration is a major contextual factor affecting the lives of women as the dislocation disrupts their social support networks, removes essential protective factors and exposes them to a series of risks that affect their reproductive health. Women in the migration process face multiple, complex risk factors and are very vulnerable to experiencing gender-based violence, including rape, yet their reproductive health is often

not prioritized in these contexts (Adanu & Johnson, 2009). Research has shown that immigrant women of color are at an increased risk for victimization upon resettlement in another country due to factors such as isolation, language barriers, traditional gender roles, lack of legal documentation, and economic insecurity (Raj & Silverman, 2002). Some of the increased risks these women experience is connected to pre-migration violence and stressors the women and their families were exposed to in their country of origin; many of the same factors that led to their migration (Guruge, Khanlou, & Gastaldo, 2009). Unfortunately, institutional barriers, such as immigration and social welfare policies, as well as cultural insensitivity make it difficult for these women to seek services (Dasgupta, 2005). If women are unable to seek services, due to fears of deportation or the inability to find a service worker who speaks their language or understands their cultural and/or religious beliefs, the women may suffer a number of negative outcomes. These outcomes could include an escalation in violence, a lack of timely and appropriate medical treatment in response to a sexual assault, or lack of family planning information or access to condoms.

The increased risk immigrant women face of experiencing gender-based violence and gender inequality also puts them at heightened risk for contracting HIV. This is especially true for refugees, as humanitarian crises, including natural disasters, but mainly armed conflict and war, create situations of heightened risk for the spread of HIV (Benjamin & Murchison, 2004; Westhoff, et al., 2008). The increased transmission of HIV results primarily from higher rates of gender-based violence, particularly sexual violence and constrained sexual decision-making (Kenny, Carballo & Bergmann, 2010;

UNFPA, 2010; Westhoff, et al., 2008). Women are at risk of infection from various modes of transmission. These include: unsafe coercive sex with intimate partners, direct transmission through rape, lack of immediate medical care including post-exposure prophylaxis following an incident of rape, as well as continued violence after discovery of her HIV+ status (Ellsberg & Betron, n.d.). Although research supports the increased risk levels women face in the context of migration, there is a scarcity of research utilizing samples of immigrant women residing in the United States that examine the role of gender-based violence and gender inequality in HIV status.

AIM AND SCOPE OF THE CURRENT STUDY

The purpose of this exploratory qualitative study is to explore the narratives of HIV+ African immigrant women to understand the role gender-based violence and gender inequality, as well as key contextual factors, have played in their constrained reproductive health decision-making and current disease status. The sample of HIV+ Black African immigrant women reside in the southwestern United States. Using narrative qualitative research methods, this study conducted in-depth semi-structured interviews to explore women's narratives on the role gender-based violence and gender inequality played in their HIV+ status. The secondary line of research inquiry sought to understand the influence contextual factors, such as poverty and migration, have on their risk for HIV infection.

Research Questions

This study specifically addressed the following broad research questions:

1) Do HIV+ African immigrant women describe experiences of gender inequality as part of their life experiences?
2) Do HIV+ African immigrant women describe encounters of gender based violence, including sexual violence, as part of their life experiences?
3) How do HIV+ African immigrant women describe their sexual decision-making?
4) Do HIV+ African immigrant women talk about contextual factors, such as poverty and migration, when they discuss their HIV status?
5) What do the stories of HIV+ African immigrant women teach us about HIV?

In summation, the study was designed to gain further insight into the contextual factors and personal experiences of HIV+ African immigrant women with the goal of identifying potential means of reducing the spread of HIV. Feminist Theory, Critical Race Theory and the Theory of Gender and Power were used to guide the exploration of the social and economic factors (such as gender, race and class) related to one's vulnerability for experiencing violent victimization, as well as negative reproductive health outcomes. These theories are discussed in more detail in Chapter Two.

The theoretical approach used in this study is innovative in that it contextualizes women's experiences and recognizes they are not always in a position to make healthy, well-informed decisions in terms of their reproductive health. Previous research on STIs

has largely focused on individual health behaviors (Amaro, et al., 2001). However, this study seeks to highlight larger structural issues (such as poverty and the status of women) that affect women's vulnerability to infection. This is an emerging topic in the scholarly literature (Gazmararian, et al., 2000). Moreover, there is a critical need for further research on immigrants, as this is a multiply marginalized population that has been effectively left out of the scholarly literature. The data collected in this study may illuminate new ways of supporting immigrant women so they have the power to lead safe and fulfilling lives free from violence and disease. Hence, the results of this study may prove useful in informing the development of HIV/AIDS risk reduction interventions.

Although this study sought to explore gender inequality and gender-based violence in its many forms, considerable focus was placed on sexual violence, as it is the form of violence that puts women at the most direct risk for HIV infection. Nonetheless, it is not always possible to tease out its distinct influence on women's health as it is perpetrated within the broader context of violence against women and intimate partner violence; both of which are influenced by a community's level of gender inequality. The scope of this study did not allow for the exploration of other global phenomenon related to gender-based violence and gender inequality, such as human trafficking, sex work, child marriages, educational disparities, and labor discrimination, etc.

This exploratory qualitative study focused on women and their experiences related to their reproductive health. The study was limited to women due to the differences in the types of violence that men and women experience. Until the last decade or so, women have historically been left out of the discourse on HIV. Therefore, this

dissertation study was designed to learn about their unique experiences and service needs, especially those of African immigrant women. Experts in the field have stated that "Feminist approaches that acknowledge women's sexuality, sexual power, and account for culture, race, and socioeconomic status in relation to HIV among women are needed to develop effective HIV prevention approaches" (Amaro, Raj & Reed, 2001, p. 326). Hence, this study sought to fill a gap in the literature by focusing on the social context surrounding women's reproductive health outcomes, specifically HIV disease status.

RESEARCHER'S INTEREST IN THE TOPIC

As a researcher, I was inspired to conduct this exploratory research for my dissertation due to my experience working and volunteering in the movement to end violence against women, including intimate partner violence and sexual violence. I am interested in learning what factors put women most at risk for experiencing gender-based violence. I am also interested in understanding the mental, physical and reproductive health consequences of gender-based violence in an effort to mitigate the multitude of risks survivors face post-victimization. In considering which population to sample for this study, I decided to work with immigrants as they are a vulnerable population largely unaddressed in the academic literature.

The theoretical underpinning for this study was informed by my previous work with colleagues from my masters' program to establish a non-profit organization to address HIV-related issues in rural western Kenya. Kenya is a former British colony located in East Africa. Through this experience, I spent one month in Kenya in 2006 and had the opportunity to talk with many people living with HIV/AIDS. I was honored to be

a witness to their strength and resilience. Furthermore, although many myths regarding HIV/AIDS still abound, we were impressed with the knowledge that local community members had regarding the disease and its transmission.

During our visit, we had the privilege of meeting many Black African women; young and old, single and widowed. They shared the stories of their lives with us, including how they were infected with the virus and the impact of the disease on their lives and the lives of their children. Although each woman's experience was unique, the theme unifying their stories was the impact of gender on their ability to protect themselves from the virus. The family and cultural prescriptions, as well as the economic insecurity associated with their gender only exacerbated their risk levels. During a particularly poignant community meeting with both men and women, a local teacher implored us to take a message back to the United States: "*We are not ignorant about HIV. It is poverty that prevents us from being able to protect ourselves against the rapid transmission of the virus."* His statement motivated me to examine the larger structural and contextual issues that increase vulnerability to HIV infection and I made a promise that day to honor his request.

Thus, I felt this dissertation was an opportunity for me to fulfill that promise, perhaps not directly to the people of Kenya, but to individuals who share similar risk factors. It is my hope that this study contributes to a deeper understanding of the complex factors influencing HIV risk levels and will inform international prevention efforts, as well as those aimed at assisting immigrants and refugees in the United States.

Chapter Two: Literature Review

GENDER-BASED VIOLENCE

When exploring the experiences of HIV+ African immigrant women, it is important to provide background information on key phenomena, such as gender-based violence, in the United States because the women in this study have been exposed to pre-migration, migration and post-migration risk factors. Therefore, we cannot assume all exposure happened while residing outside of the country. On the contrary, some of the women encountered gender-based violence and inequality while living in the United States. Hence, it is important to understand both the national and the international context of their lives.

National Prevalence Rates of Gender-based Violence in the United States

Gender-based violence is a major public health concern in the United States. While some of this violence is perpetrated by strangers, the majority is perpetrated by people known to the individual (Tjaden & Thoennes, 2000). The Council on Women and Girls (2011) estimates that 26% of violence against women is committed by an intimate partner. The rate for men is significantly lower (5%). One in four women experience some form of intimate partner violence as an adult (Tjaden & Thoennes, 1998). A telephone survey of 3,568 women participating in a health maintenance organization (HMO) found 44% adult prevalence rates, compared to approximately 12% in the last five years and 6% in the last one year (Thompson, et al., 2006). Research has also shown that women who experience intimate partner violence often suffer negative health outcomes, such as physical ailments (Campbell, 2002; Ullman & Brecklin, 2003), mental

health issues (Bonomi, Andersen, Rivara & Thompson, 2007), and substance use disorders (El-Bassel, Gilbert, Schilling, & Wada, 2000), as well as reproductive disorders (Golding, 1996; McFarlane, et al., 2005).

One main form of interpersonal violence, and one that puts women at the most direct risk for contracting STIs including HIV, is sexual violence. The National Violence Against Women Survey (NVAWS), a nationally representative study, estimated that 7.75 million women have been raped by an intimate partner in their lifetime (Tjaden & Thoennes, 2000). Approximately 18% of the women who participated in the study were raped as an adult (Tjaden & Thoennes, 2000). For purposes of the survey, rape was defined as "forced vaginal, oral, and anal sex" (Tjaden & Thoennes, 2000, p. 13). The large majority of these acts of violence were perpetrated by an intimate partner (62% versus 21% by acquaintances and 17% by a stranger). The same results regarding lifetime occurrence, of approximately one in five women, were found in a later study conducted by Kilpatrick and colleagues in 2007. They also estimated that more than 1 million women were raped during the year prior to the study.

Most previous studies on sexual violence have focused on rape and/or attempted rape and have largely ignored the issue of sexual coercion (Basile, 2002). Therefore, reliable information regarding the prevalence of coercive acts of sexual violence is limited. Nonetheless, in a nationally representative study, the number of women raped increased to 34% when lifetime sexual coercion (which may or may not include physical force or threat of force) by an intimate partner was considered (Basile, 2002).

Sexual Violence within the Context of Intimate Partner Violence

Although often viewed as a crime perpetrated by strangers (Anderson, 2007), sexual violence is perpetrated by other individuals as well, including acquaintances or intimate partners (Tjaden & Thoennes, 2000). In fact, the majority of incidences are perpetrated by intimate partners (Tjaden & Thoennes, 2000), which are defined as "current and former dates, spouses, and cohabitating partners" (Tjaden & Thoennes, 1998). Data from the Bureau of Justice Statistics (2005) estimates that approximately 70% of women who are raped know the perpetrator. Hence, research has revealed that individuals already known to the survivor are more likely to perpetrate sexual assault than strangers (Randall & Haskell, 1995; Tjaden & Thoennes, 2000b). While physical and psychological violence by intimate partners have been widely studied, sexual violence within abusive relationships is less explored (Campbell & Soeken, 1999).

As an emerging topic, sexual violence is often viewed as either an immersed form of intimate partner violence or as a "separate phenomenon" (Campbell & Soeken, 1999, p. 1018). Reducing our understanding of sexual violence into simply one form of intimate partner violence does not facilitate a full understanding of the unique impact and meaning of the sexualized nature of the violent act. On the other hand, examining it as a "separate phenomenon", such as one would study rape, provides a false connotation of violence perpetrated by a stranger (Campbell & Soeken, 1999). It also ignores the distinct dynamics of intimate partner violence in which the threat and/or use of violence is used as a tool by which to exert power and control over an intimate partner. This lack of recognition of sexual violence as a distinct form of violence, yet fully integrated within

the context of intimate partner violence, has led to difficulties in effectively defining the phenomenon and accurately collecting data on its occurrence (Campbell & Soeken, 1999).

While some survivors of intimate partner violence experience only one form of violence, many experience multiple forms either concurrently or sequentially (Kramer, Lorenzon, & Mueller, 2004). In fact, women involved in abusive relationships experience particularly high rates of sexual violence. A number of studies have indicated that 40-45% of women in abusive relationships have experienced forced sex by their intimate partner (Campbell, 1989; Campbell & Soeken, 1999). Interviews of women filing for a protective order showed very similar rates; an astounding 68% of women who experience physical violence also experienced sexual assault (McFarlane, Malecha, Watson, Gist, Batten, Hall, & Smith, 2005). A study by Wingood, DiClemente, and Raj (2000) of women residing in domestic violence shelters revealed that 55% had experienced physical violence, as well as sexual violence. Elsewhere, among women seeking medical services, an astonishing 88% reported experiencing sexual and psychological abuse, while 44% reported experiencing sexual and physical abuse (Kramer, et al., 2004).

Moreover, many of the women who experience sexual violence in the context of intimate partner violence experience multiple incidences. In fact, Thompson and colleagues (2006) found that 13.8% of women who experienced forced sex in the context of intimate partner violence reported 20 or more incidences throughout their adulthood. These findings point to the complexity of this phenomenon, as well as the possible range and severity of the negative outcomes faced by survivors. Nonetheless, using data

provided by the National Crime Victimization Survey, the Council on Women and Girl's Report, *Women in America,* (2011) confirms that sexual violence is an underreported crime and estimates that only about half of rapes are reported to law enforcement officers.

International Gender-based Violence Prevalence Rates

Gender-based violence is a wide-spread phenomenon throughout the world. As in the United States, a large portion of the violence committed against women is perpetrated by intimate partners. Although it is challenging to compare prevalence rates between nations (Watts & Zimmerman, 2002), research has shown that national rates do vary significantly (Glasier, et al., 2006). According to the World Health Organization's *Multi-country Study on Women's Health and Domestic Violence*, somewhere between 13% and 61% of ever married women have experienced intimate partner violence in the form of physical violence during their lifetime (Garcia-Moreno, Jansen, Ellsberg, Heise & Watts, 2006). According to the Centers for Disease Control and Prevention, approximately one third of all the women in the world have been abused at some point in their life (Hynes & Cardozo, 2000, p. 819). The international report, which was developed from interviews with 24,000 women in ten different nations, found that economic gender inequality, attitudes regarding gender roles, and efforts by family and community members to intervene, all impacted women's risk of experiencing intimate partner violence (WHO, 2005). In terms of sexual violence, the report estimated almost the same rate (between 6% and 59%). In fact, over the course of their lifetime as many as one quarter of the women in some nations are raped within the context of an intimate relationship (Jewkes, Sen, & Garcia-Moreno, 2002). Staggeringly, in Zimbabwe for example, one-fifth of the

ever married women who reported being raped cited at least one incident within the last 12 months (Watts & Zimmerman, 2002). Exact percentages of gender-based violence are hard to obtain for any country. The challenges are even greater for nations, such as some of those in sub-Saharan African nations, in which these issues are believed to be private family matters and, thus, not openly discussed.

Sexual violence, the form of gender-based violence that puts women at the most direct risk for contracting HIV, takes on a variety of forms across the globe. Some examples of the international context in which sexual violence occurs were listed by Watts and Zimmerman (2002). These include: drug-facilitated date-rape, forced marriage, and gang initiations, as well as survival sex, which is defined as a transaction in which an individual sells sexual services in order to be able to meet their basic needs, such as housing and food (Greene, Ennett, & Ringwalt, 1999).

At-risk Populations

There are many factors that affect one's vulnerability for experiencing gender-based violence. Therefore, it is essential that empirical research determine which factors are most closely associated with risk for victimization, as this information can be utilized in the critical work of creating social change in order to prevent future incidences of violence against women. This section discusses some of the most influential of these risk factors, especially in terms of sexual violence, the form of violence that puts women at the most direct risk of contracting STIS, including HIV. Moreover, this section focuses on macro-level socioeconomic factors impacting women, as there is an overemphasis on

individual-level factors in this current academic climate which is largely focused on health behaviors (Amaro, et al., 2001).

Race/Ethnicity

Discussions based on race as a risk factor for victimization are somewhat perplexing and controversial. The traditional discourse on sexual violence, as well as other forms of violence against women, has focused on the fact that violence occurs within all racial and economic groups and, therefore, does not discriminate (Sokoloff & Dupont, 2005). However, research shows that race does impact one's likelihood of experiencing sexual violence and that women of color carry a heavy burden in relation to the incidence of sexual violence. According to the National Violence Against Women Survey, it was determined that women of color are more likely to experience sexual violence than are white women (Tjaden & Thoennes, 2000). The same is true when examining the prevalence of sexual violence committed by intimate partners (Tjaden & Thoennes, 1998). Research has also shown that the negative reproductive health outcomes women experience are exacerbated if the survivor is a woman of color (Amaro, et al., 2001).

It should be noted here that the use of the term "women of color" is not meant to lump together a very heterogeneous group. Although racism makes women of color more vulnerable to experiencing violence, victimization rates vary greatly among groups. The same is also true for STI and HIV infection rates. Thus, it is important to recognize the diversity of women encapsulated in this term. For example, this study is interested in the reproductive health of Black African-born women who immigrated to the United States.

These women have different experiences and struggles from African American and/or Black women born in the United States. In addition to discrimination based on their race and gender, they also face challenges related to being an immigrant, including lingual and cultural differences. It is essential to make these distinctions as collecting information related to particular groups of women helps in the prevention and treatment of the HIV epidemic, as well as calls for culturally tailored programming specifically designed for their needs (Kerani, et al., 2008).

Nonetheless, despite their diversity, feminist scholars have declared that women of color face significant institutional barriers in accessing services (Collins, 2004). Incite!, a national organization working to end violence against women of color, argues that "women of color do not just face quantitatively more issues when they suffer violence … but their experience is qualitatively different from that of white women" (Incite!, 2009). Therefore, the traditional oversimplification of violence, including sexual violence, may lead to a continued reliance on interventions and programs developed by white middle-class women at the exclusion of marginalized women (Richie, 2000); programs which may be ineffective in serving the needs of women of color (Crenshaw, 1991). Nonetheless, conflicting research does exist with some studies failing to detect a difference in victimization rates by race (Basile et al., 2006). In fact, using data from the National Crime Victimization Survey, the Council on Women and Girls (2011) asserted that Black women actually have lower rates of intimate partner violence.

Sokoloff and Dupont (2005) argue that our analysis of the higher victimization rates of women of color must include an acknowledgement that these differences spring

from structural issues, as opposed to individual differences. These macrolevel issues center around racisim, classism and even colonialism (Sokoloff & Dupont, 2005). Thus, it is important to recognize that prevalence rates are exacerbated not by one's race itself, but by social and economic factors, such as marginalization and poverty (Sokoloff & Dupont, 2005), factors very relevant in the lives of HIV+ immigrant women.

Research on STI transmission helps illustrate the debate on race by highlighting the mechanisms through which race is linked to higher infection rates. STI infection rates are substantially higher among African Americans when compared to whites (Farley, 2006). Research conducted by Adimora and Schoenbach (2005) emphasize the impact of poverty, racial discrimination and even segregation. Thus, Adimora and Schoenbach advocate for moving the focus away from individual behavior to larger structural issues (see also Farley, 2006). Farley (2006) goes even further by declaring that race is simply a "marker" for the larger socioeconomic factors (p. 58).

As with sexual violence, discussion of STI transmission rates can be stigmatizing to already marginalized populations and, thus, difficult to discuss (Farley, 2006). Nonetheless, Farley argues "that there should be a benefit to understanding what race is a marker for, that is, the sociological implications of race that ultimately lead to higher rates of [STIs]" (Farley, 2006, p. 59). This study makes the same argument regarding rates of violent victimization. Therefore, regardless of the exact percentage rate of violence against women of color in comparison to white women, it is essential to pay attention to the additional form of oppression experienced by women of color and to recognize its impact on their safety.

Class

Researchers argue that prevalence rates are exacerbated by social and economic factors, such as marginalization and poverty (Sokoloff & Dupont, 2005), as well as social inequalities (MacKinnon, 2003). Thus, numerous researchers assert that poverty increases women's vulnerability to violence (Jewkes, 2002; Jewkes, et al., 2002; NSVRC, 2004). Poverty can leave women vulnerable to exploitation, including coercion and survival sex, which put women at risk for experiencing violence (Jewkes, 2002). As previously argued, Jewkes stresses that many of the differences in the prevalence of sexual violence that are thought to be based on race and ethnicity are actually due to poverty. In addition, research has shown that the negative reproductive health outcomes women experience are amplified if the survivor is poor (Amaro, et al., 2001). It is very important to understand the influence of poverty in the lives of women, as it is one of the main contextual issues of interest in this study. Furthermore, because this study explores the experiences of immigrant women, it is assumed that some of the women may have experienced poverty at some point in their lives, either as a push factor propelling their migration or as an, at least temporary, consequence of resettling to a new country and seeking employment.

Education

Educational levels are related to poverty. Interestingly, research has found that when women increase their education, they are at a higher risk for experiencing violence, as this form of empowerment can appear as a significant threat to a male partner's dominance (Jewkes, et al., 2002). Thus, although education and income can sometimes serve as protective factors for women, the effect of these factors are not linear (Jewkes,

2002). In reality, violence can actually escalate during transitional periods, or periods marked by improvements in women's educational and economic status (Jewkes, 2002). Jewkes (2002) further argues that transitions involving women's move away from traditional gender roles may also lead to violence. Hence, men may use violence to define their identity and assert their masculinity over their partner in order to overcome a sense of personal powerlessness (Jewkes, 2002). Education is expected to play an interesting role in the lives of the women in this study as educational and occupational opportunities may change dramatically in the pre-migration versus post-migration lives of immigrant women. As mentioned, these changes are often associated with fluctuations in women's performance of traditional gender roles. Therefore, it is uncertain whether these changes will serve as a protective factor or a risk factor in the lives of these women.

Age

Age has also been shown to factor into one's vulnerability to experience interpersonal violence. For example, older women are at a lower risk for experiencing sexual violence than younger women (Acierno, Resnick, Kilpatrick, Saunders, & Best, 1999; Jewkes, et al., 2002). Using 2003-2008 data from the National Crime Victimization Survey, the Council on Women and Girls (2011) found intimate partner violence was highest among young women (age 20-24) and lowest among women over the age of 65. Disturbingly, one study estimated that young women below age 15 represent between one-third to two-thirds of all survivors of sexual assault (Heise, Pitanguy, & Germain, 1994). Early victimization often leads to patterns of ongoing risk throughout the life course. Nonetheless, the discrepancy in victimization estimates based on age could be

generational due to the evolution of the public discourse on violence against women and, thus, differences in perceptions regarding their experiences. For example, women from an older generation may be less likely to report incidences of sexual violence because they may not readily dentify their experiences as such (González-López, personal communication, August 1, 2013).

GENDER INEQUALITY

Gender inequality can have a significant impact on women's experience with gender-based violence, particularly sexual violence. In fact, gender is the most influential risk factor when considering one's vulnerability for experiencing sexual violence. Although men also experience intimate partner violence and sexual violence, the vast majority of survivors are women (Tjaden & Thoennes, 2000). MacKinnon (2003) identifies sexual violence in terms of social inequality and power imbalances based on gender. MacKinnon asserts "rape is not so much an act of violence or sex as it is an act of sex inequality" (p. 267). Other influential forms of domination include race, class and age (MacKinnon, 2003, p. 269). Watts and Zimmerman (2002) take this argument even further by stating that all forms of violence against women act to reinforce and strengthen the social hierarchies that place women below men. Women's lower social status relative to men is disempowering and decreases their sense of sexual self-efficacy (Amaro, Raj & Reed, 2001). Women, especially impoverished women, are also vulnerable to sexual exploitation in which "sexual favors are demanded in exchange for goods or services such as food, shelter, water, and protection among others" (Benjamin & Murchison, 2004,

p. 15). As economic vulnerability increases, the risk of sexual exploitation also increases (Benjamin & Murchison, 2004).

Researchers, such as MacKinnon (2003), argue that sexual violence, similar to other forms of violence against women, is not inherent in society, but instead is fueled by social inequalities. Thus, it can be extrapolated that societies with higher levels of inequality will experience higher levels of victimization. Hence, risk factors related to social hierarchies, such as gender inequality, are of special influence (MacKinnon, 2003). MacKinnon (2003) argues that this is because gender is the strongest demarcation of power differentials. Rigid customs designed to control women's sexuality also put them at a heightened risk (UNFPA, 2010). Furthermore, male entitlement which is closely related to gender inequality further facilitates sexual violence (Jewkes, et al., 2002; NSVRC, 2004).

The work of González-López (2005) with Mexican immigrants has informed our understanding of the impact of culture on gender inequality. Although, González-López's work examines the impact of life in Mexico, her keen insights can be used to understand other locations and cultures, as well. She argues that gender performance is fluid and influenced by one's social context. González-López coined the phrase *"regional patriarchies"* in order to demonstrate that the nature and impact of patriarchy is not uniform across a culture or even a nation. She states further:

> By proposing the terms regional patriarchies I seek to explain how women and men are exposed to diverse, fluid, and malleable but regionally uniform and locally defined expressions of hegemony and their corresponding sexual

moralities. While shaped by the socioeconomics of a local region, each one of these patriarchies takes myriad forms and promotes various levels of gender inequality" (González-López, 2005, p. 6).

THE ROLE OF GENDER-BASED VIOLENCE IN WOMEN'S NEGATIVE HEALTH OUTCOMES

This study sought to engage in an exploration of gender-based violence, particularly sexual violence, and its influence on women's overall health with a special focus on reproductive health, including the transmission of STIs particularly HIV. As previously mentioned, it is difficult to extract sexual violence's exact unique effect due to its interlaced relationship with gender-based violence and intimate partner violence. Gender-based violence is often used as an umbrella term for a variety of forms of violence against women. This study was particularly interested in intimate partner violence (which includes physical, sexual and emotion abuse by an intimate partner), as well as sexual violence which may be perpetrated by an intimate partner, family member, acquaintance or stranger. Often times, unless otherwise stated, research on intimate partner violence is concerned primarily with physical violence. In order to be inclusive, this section on the empirical research regarding health issues examined gender-based violence, including sexual violence, perpetrated by intimate and non-intimate partners.

There are a variety of negative health outcomes women who experience intimate partner violence often suffer. These health issues will be explored in more detail in the following sections. Research has shown that some survivors of intimate partner violence experience negative physical health outcomes. These outcomes include direct injury, as

well as physical ailments, such as chronic stress and gastrointestinal problems (Campbell, 2002; Ullman & Brecklin, 2003). Other survivors may experience mental health related issues, such as substance use disorders (El-Bassel, Gilbert, Schilling, & Wada, 2000), depression (Bonomi, et al., 2007), and post-traumatic stress disorder (Bennice, Resick, Mechanic, & Astin, 2003). Finally, others may experience reproductive problems. These problems may include vaginal infections and chronic pelvic pain (Golding, 1996; McFarlane, et al., 2005). Moreover, the power and control exercised against women in these relationships creates substantial barriers for women to make informed decisions about contraceptives, as well as successfully negotiating their use (Wingood & DiClemente, 1998). Therefore, intimate partner violence can lead to the transmission of sexually transmitted infections (Allsworth, Anand, Redding, & Peipert, 2009; El-Bassel, et al., 1998).

Physical Health

Research has shown that many survivors of intimate partner violence experience negative physical health consequences related to the violence they have experienced and report a lower quality of health (Bonomi, Anderson, Rivara & Thompson, 2007; Campbell, et al., 2002; Kramer, et al., 2004). A review of the literature has demonstrated a link between intimate partner violence and injury, chronic stress, chronic pain and gastrointestinal problems (Campbell, 2002). Moreover, a telephone survey of women participating in a health maintenance organization (HMO) found that female survivors often exhibit gynecological, central nervous system, and stress-related problems at a rate of 50% to 70% higher than non-abused women (Campbell, et al., 2002). Common health

problems include headaches, digestive issues and back pain. Negative outcomes were more severe for women who have experienced sexual violence, compared to only physical violence (Campbell, et al., 2002). This suggests that sexual violence may be a particularly influential factor in women's health.

A study using data from the National Comorbidity Survey examined the mental health and substance abuse problems of women who experienced sexual violence and its relationship to recent chronic medical conditions (Ullman & Brecklin, 2003). The authors divided sexual victimization into three groups: those assaulted only as children, those assaulted only as adults, and those who experienced sexual assault during both phases of life. Findings indicated that women who were sexually assaulted during child and adulthood had higher rates of recent chronic medical conditions and more contact with mental health and substance abuse service providers than those who had not experienced sexual assault. Among women who were sexually assaulted during adulthood, the experience of other traumatic life events (such as accidents, natural disasters or witnessing violence) increased their risk for chronic medical conditions, such as stroke, AIDS, cancer, diabetes and heart disease.

Mental Health

As sexual violence frequently occurs within the context of intimate partner violence, it is important to understand the impact intimate partner violence has on survivors, many of which are the same as the impacts experienced directly from sexual violence. In addition to having a lower perceived quality of physical health (Kramer, et al., 2004), women who experience intimate partner violence (generally speaking in the

form of physical violence) are also at a higher risk for developing a variety of mental health problems, such as depression (Campbell, 2002; Campbell, Kub, Belnap, & Templin, 1997; Kramer, et al., 2004, Liebschutz, et al., 1997), post-traumatic stress disorder (Campbell, 2002; Kemp, Green, Hovanitz, & Rawlings, 1995; Liebschutz, et al., 1997; Saunders, 1994), substance abuse disorders (El-Bassel, Gilbert, Schilling & Wada, 2000; Golding, 1999; Kramer, et al., 2004; Leadley, Clark & Caetano, 2000), anxiety (Liebschutz, et al., 1997), suicidal thoughts (Kramer, et al., 2004; Liebschutz, et al., 1997), and low self-esteem (Campbell, 1989). In fact, a meta-analysis on intimate partner violence as a risk factor for mental health problems found 47.6% of survivors suffer from depression, 17.9% are suicidal, and 63.8% have post-traumatic stress disorder (Golding, 1999).

Sexual Violence and Mental Health

Moving away from the discussion on intimate partner violence (focusing mainly on physical violence), there is a growing body of literature on the adverse consequences associated with sexual violence victimization. A number of previous studies point to the relationship between sexual violence victimization and mental health disorders (Campbell & Soeken, 1999; Coker et al., 2002; Goodman, Stanley, Rosenberg, Mueser & Drake, 1997; Hutchings & Dutton, 1993; Roberts, Williams, Lawrence, & Raphael, 1998) and substance use disorders (El-Bassel, Gilbert, Schilling, & Wada, 2000; Kramer, et al., 2004; Leadly, Clark & Caetano, 2000; Ullman & Brecklin, 2003). In the scientific literature, sexual violence in intimate partner relationships has been found to be associated with depression (Bonomi, et al., 2007; Campbell & Soeken, 1999), post-

traumatic stress disorder (Bennice, Resick, Mechanic, & Astin, 2003; McFarlane, et al., 2005), suicidal ideation (Golding, 1999) and anxiety (Liebschutz, Mulvey, & Samset, 1997). Links to negative body image and decreased self-esteem have also been found for survivors who experienced sexual violence in the context of intimate partner violence (Campbell, 1989).

In addition, studies on adults show that individuals receiving mental health services exhibit high rates of sexual victimization. A study conducted at a community mental health center indicated that a total of 48% of all individuals receiving services had been sexually assaulted or abused (Hutchings & Dutton, 1993). Similarly, research has revealed that women with serious mental illness experience rates of lifetime sexual and physical violence as high as 51% to 97% (Goodman, et al., 1997). Although there is evidence that mental health and substance use disorders can make individuals more vulnerable to abuse (Jewkes, et al., 2002), a number of studies have found that trauma, especially that of a sexual nature, often tends to precede these disorders (Gatz, et al, 2005; Horwitz, Widom, McLaughlin & White, 2001; Molnar, Buka & Kessler, 2001).

Reproductive Health

Further research needs to be conducted in order to determine the nature and extent of the impact of interpersonal violence on reproductive health (Gazmararian, et al., 2000; McMahon, Goodwin, & Stringer, 2000) and rights. Nonetheless, it is known that intimate partner violence, including sexual violence, has been connected to various reproductive health problems. In a review of American and Canadian nationally-representative surveys conducted between 1985 and 1998, Campbell (2002) found that gynecological problems

are approximately three times more common among women with a history of abuse than their non-abused counterparts. In fact, gynecological issues signify the most significant and enduring health-related problems among women who have been abused (Campbell, 2002). This review specifically mentioned "sexually-transmitted diseases, vaginal bleeding or infection, fibroids, decreased sexual desire, genital irritation, pain on intercourse, chronic pelvic pain, and urinary-tract infections" as women's reproductive health problems directly associated with intimate partner violence (Campbell, 2002, p. 1332; see also McFarlane, et al., 2005).

Moreover, research has shown that women who experienced sexual violence had statistically higher rates of painful menstruation, irregular menstrual periods, excessive menstrual bleeding, missed periods, genital burning, sexual indifference, pain during intercourse and lack of sexual pleasure (Golding, 1996). Survivors of repeated sexual assaults and those assaulted by spouses were more likely to experience *sexual symptoms*, such as lack of sexual pleasure. In contrast, survivors of sexual violence committed by a stranger or with pronounced physical violence were more likely to develop *reproductive symptoms*, such as excessive menstrual bleeding (Golding, 1996). This study was conducted using a random sample (N=3,419) of women from two cities who participated in an epidemiological study funded by the National Institute on Mental Health. Of these women, 362 reported a lifetime history of sexual violence. Although the study used a single-item question to identify survivors of sexual violence (which it is assumed led to underreporting), the strength of the study was that it took the type of sexual assault into

consideration, as well as the number of incidences and the survivor's relationship to the perpetrator (Golding, 1996).

Research has also indicated that sexual violence may have an even greater impact than physical violence on reproductive disorders. In a case-control study (N=2,005) comparing 201 previously abused women with 240 women without histories of abuse who were identified through their membership in a health maintenance organization (HMO), Campbell and colleagues (2002) found that compared to 8% of women who only experienced physical violence, 30% of women who experienced sexual violence (with or without physical violence) had three or more gynecological problems (Campbell, et al., 2002). The study was conducted through telephone interviews. Limitations of the study include the fact that the researchers did not separate sexual violence from physical violence. In addition, the sample was over- representative of educated, middle class women and the study looked at abuse over the course of the last eight years, as opposed to lifetime occurrence.

Contraceptive Control and Reproductive Coercion

In order to understand how intimate partner violence, and sexual violence in particular, can lead to negative reproductive health outcomes, such as STIs including HIV, it is essential to first understand the mechanisms through which this occurs. Thus, this section will begin with an overview of the dynamics associated with contraceptive control and reproductive coercion.

It is well documented that intimate partner violence is characterized by dynamics of power and control exercised by the perpetrator (Hamberger, Lohr & Bonge, 1994).

Perpetrators' use of these methods creates a substantial barrier for women in making well-informed decisions, free from coercion, concerning their desires and plans for conceptive use. A qualitative study using a sample of ten women seeking therapeutic services for intimate partner violence and/or sexual violence showed that many of the female participants felt their partner used the refusal or use of contraception as a means of control in their relationship (Coggins & Bullock, 2003). These women's experiences pointed directly to a desire by the abusers to control them and remove their decision-making ability. In fact, many felt helpless to control their sexuality, for example whether to have sex and with what contraception, even though they were fearful of becoming pregnant (Coggins & Bullock, 2003). Utilizing focus groups, the study provided rich data on the experiences of women seeking therapeutic services. However, there were some problems with the study in that only one of the ten participants was from the community, all the rest were from a shelter. This uneven sampling, plus the fact that it was a largely low-income sample, may skew results. Nonetheless, the dynamics discussed above are of special importance regarding contraceptives and successfully negotiating their use, as research shows that women are less likely to request their partner use a condom if they are afraid of a violent reaction to the request (Wingood & DiClemente, 1998). These findings were discovered through face-to-face interviews discussing risky sexual behaviors with a sample of 180 African-American women (Wingood & DiClemente, 1998).

The reproductive health of women can be greatly influenced by women's lower status in society which acts to reduce their sexual autonomy (Amaro, et al., 2001; United

National Population Fund [UNFPA], 2010). This is due, in large part, to a patriarchal system in which the sexual needs and desires of men are valued over those of women (Tolman, Spencer, Rosen-Reynoso & Porche, 2003 as cited in Impett, Schooler & Tolman, 2006). This social context can lead to the diminished reproductive health of women (Impett, et al., 2006). Thus, the general social status of women has a damaging effect on their ability to exercise agency over contraceptive decisions. The World Health Organization has declared that "individual choices and behaviors are embedded in many layers of social and community context, from marriages and extended families, to communities and countries" (World Health Organization, 2010, p. 1).

Perpetrators' use of control tactics to dictate contraceptive use is referred to as reproductive coercion. It is defined as follows: Reproductive coercion spans both pregnancy coercion (e.g., male partners' verbal pressure to get women pregnant) and birth control sabotage (e.g., condom manipulation and other active interference with contraceptive methods) and results in women's compromised decision-making regarding, or limited ability to enact, the use of condom and other contraceptives (Miller, et al. 2010).

A research study regarding the sexual risk levels of adolescent women with experiences of intimate partner violence highlights this situation. The study found that these young women were at a higher risk for engaging in risky sexual behavior, such as having multiple sex partners, as well as facing various forms of reproductive coercion, such as partners' refusal to use a condom or using intimidation to end discussions regarding condom use (Silverman, et al., 2011). This study used a convenience sample of

356 youth seeking services at adolescent health clinics. The study looked at lifetime intimate partner victimization and utilized the Conflict Tactics Scale but did not differentiate findings regarding sexual or physical violence. As many of the studies on related topics, this study relied on self-report which can lead to underreporting, furthermore, because the study is not longitudinal, it is difficult to say if the intimate partner violence preceded the sexual risk behaviors examined (Silverman, et al., 2011).

Sexually Transmitted Infections

Reproductive coercion, as well as the lack of control over contraceptive use, leaves women vulnerable for contracting sexually transmitted infections (STIs). Research has shown that survivors of intimate partner violence have higher rates of STIs. In a study of 143 women of color, including Latinas and African American women, seeking medical services in an urban emergency department, El-Bassel and colleagues (1998) found that women with a history of intimate partner violence were at a five times higher risk for contracting an STI than women without such a history. They were also much more likely to engage in a variety of risky sexual behaviors. Unfortunately, this study did not make a distinction between physical and sexual violence and, as many similar studies, it was a cross-sectional study relying on self-report which makes assessing causal relationships difficult (El-Bassel, et al., 1998). Similarly, in a study of 542 female survivors age 13 to 35 that tracked STI incidents over a two year period, Allsworth and colleagues (2009) found that interpersonal violence was associated with shorter periods of time before STI contraction. Interestingly, the study indicated that recent (within the last year) physical violence had a higher association to STI incidents than physical and sexual violence, or

just sexual violence. The authors admitted that this finding contradicts previous research and state that the differences may be due to the small sample of women reporting sexual violence or to ambiguity in the distinction between physical and sexual violence (Allsworth, et al., 2009).

Women's histories of both physical and sexual violence are associated with increased STI rates (Martin, et al., 1999). Through a study of 774 women seeking medical services at prenatal clinics in which data was collected through interviews, Martin and colleagues discovered that women who experienced physical and sexual violence were more likely to have contracted an STI that those who only experienced physical violence or did not experience any violence at all. Limitations of this study include the fact that only a single question was used to assess sexual violence. The same procedure was also used for physical violence (Martin, et al., 1999). Moreover, as mentioned with other studies, this study relies on self-report. Perhaps future studies conducted in medical facilities will have the ability to confirm infection rates through the review of medical records. In addition, sexual violence was not examined separately, as was physical violence. In a study of 203 survivors living in domestic violence shelters assessing for abuse within the last 60 days, Wingwood and colleagues (2000a) found that women with histories of both sexual and physical intimate partner violence experienced more STIs than those who just experienced physical violence.

Histories of sexual violence without other forms of violence also seem to lead to greater STI risk levels. The study mentioned above also highlighted the increased risk of STI contraction for women who have been raped (Wingwood et al., 2000b). Specifically,

the study found that approximately one third of the women blamed an abusive intimate partner for giving them an STI. The generalizability of this study is limited due to the small shelter-based sample it used, as well as its reliance on self-report regarding STI infection (Wingwood, et al., 2000a). Other research has shown that the effect of sexual violence on STI transmissions can be very direct. For example, a study examining the experiences of 148 women seeking protective orders found that some incidents of STI transmissions were a direct result of incidents of sexual violence (McFarlane, et al., 2005).

HIV

Decades of research has shown that violence against women and gender inequality are both associated with increased risk for contracting HIV as they prevent women from making healthy reproductive choices and instead lead to unsafe sex (Madzimbalale, Khoza, Lebese, & Shilubane, 2011). That's why research has shown effective HIV prevention efforts should include components to address gender-based violence and gender inequality (Gomez, 2011). Unfortunately, while HIV prevalence rates are generally decreasing in the United States, cases among women have increased astronomically from 7% in 1985 to 25% in 2008 (Gomez, 2011). Most of these new infections in women are among women of color (83%) and the vast majority (85%) are from heterosexual sex (Gomez, 2011). Furthermore, physiological factors put women at further risk for contracting HIV as the virus is transferred more readily from men to women than visa versa (Benjamin & Murchison, 2004).

One study estimates that 12% of women who are HIV+ were infected as a result of intimate partner violence (Sareen, Pagura, & Grant, 2009 as cited by Madzimbalale, Khoza, Lebese, & Shilubane, 2011). According to a 1992 report by the National Association of People with AIDS, the rate is even higher at 25% to 50% of women with STIs, including HIV (as cited in Champion & Shain, 1998). Not surprisingly then, research has shown that women with a history of sexual assault are overrepresented among individuals who are HIV positive (Brady, Gallagher, Berger, & Vega, 2002). Brady and colleagues (2002) revealed this finding through a review of the medical charts of 100 women participating in an HMO for people living with AIDS. Even higher rates are reported for STIs in general.

Amaro and colleagues (2001) shed light on these dynamics relating to risk for STI contraction. Through a historical analysis of the US HIV epidemic, they investigated the risk for contracting HIV and found that male-controlled sexual decision-making, male use of intimate partner violence, and histories of sexual assault increased women's level of risk for contracting the disease. The difficulties women faced were exacerbated if she lived in poverty, was a women of color, or abused drugs or alcohol (Amaro, et al., 2001).

Despite the research supporting this correlation, a study of 21 domestic violence shelters revealed that although shelter staff are knowledgeable about the connection between intimate partner violence and HIV, they are inadequately prepared to offer programming to reduce their residents' risk of contracting virus (Rountree, Pomeroy & Marsiglia, 2008). This was true even though approximately 85% of the participating shelters felt this programming could be beneficial (Rountree, et al., 2008). Barriers

preventing domestic violence shelters from offering HIV prevention programming include: staff training requirements, lack of funding, other programming priorities and a lack of collaborative program partners (Rountree, et al., 2008). These results point to a need for domestic violence shelters to empower residents by providing them with information on how to minimize their increased risk for contracting HIV (Rountree, et al., 2008). Nonetheless, research has shown that survivors need assistance to engage in culturally competent sexual safety planning that takes their unique experiences and situations into account (Rountree & Mulvaney, 2008).

THE ROLE OF MIGRATION IN GENDER-BASED VIOLENCE, GENDER INEQUALITY AND REPRODUCTIVE HEALTH, PARTICULARLY HIV

As previously mentioned, the literature on factors influencing women's vulnerability for experiencing gender-based violence, particularly sexual violence, and reproductive health outcomes, such as HIV infection, has focused heavily on individual factors (Koss & Dinero, 1989). Nonetheless, research has shown that in order to broaden our understanding of the factors that increase women's risk of experiencing sexual violence, it is essential to examine environmental factors as well (Wiest, Mocellin & Motsisi, 1994). Environmental/contextual factors are particularly pronounced and powerful during and following a humanitarian crisis, such as a war or natural disaster. This is an emerging topic in the literature, for which there is a need for further research and examination (March, Purdin & Navani, 2006).

Nonetheless, previous research has shown that humanitarian crises have uneven impacts based on one's gender. Amaratunga and O'Sullivan (2006) asserted that unjust

social structures, such as those imposed by poverty, dictate who will suffer the most in the face of a disaster. Furthermore, researchers have argued the unequal distribution of negative outcomes that result from disasters is not spontaneous or accidental. Instead, they are a clear reflection of the "sets of unequal access to opportunities and unequal exposures to risks" inherent in our society (Canon, 1994, p. 14, as cited in Neumayer & Plumper, 2007, p. 552). Due to the patriarchal nature of society, these factors dictate that women are faced with the burden of this unequal distribution. Thus the section below will explore the contextual factors affecting immigrants and refugees and highlight the manner in which these factors increase their risk for experiencing gender-based violence and gender inequality, as well as contracting HIV.

Immigrants and Refugees

Forced migration is on the rise due to armed conflict, political instability, natural disasters, and food shortages (Pumariega, Rothe, & Pumariega, 2005). In fact, forced migration is so high that "it is considered that one out of every 135 people alive in the world today is a 'refugee'" (UN High Commission on Refugees, 2000 as cited by Pumariega, Rothe, Pumariega, 2005, p. 582). In 2011, 9.9 million refugees were resettled across the world, of those 56,424 were resettled in the United States (Hyde & Coffman, 2011). Women and children make up the majority of these populations (Mikolajczyk, Maxwell & Eljedi, 2010). "According to the United Nations High Commissioner for Refugees, a refugee is someone who has left the country of her nationality because she fears being persecuted" (Hynes & Cardozo, 2000, p. 819). Furthermore, someone who has been granted refugee status by the United Nations is not safe to return to their country

of origin due to fear of persecution (often due to discrimination based on race, religion or political affiliation) (Hyde & Coffman, 2011). Refugees have undergone tremendous hardship and trauma, therefore, they enjoy special protections once they are resettled in the United States. Immigrants do not have the same protections as their migration is considered voluntary, nonetheless, they often faced constrained choices due to chronic economic and political situations in their country of origin.

Refugees, and some immigrants, go through a number of stressors before them embark on the migration process. Pumariega, Rothe and Pumariega (2005) list some of these stressors as "war, torture, terrorism, natural disasters, famine" also "loss of extended family and kinship networks" (p. 583). These stressors are often magnified based on the length of stay in refugee camps, or other temporary housing, as well as having to cross international borders without the appropriate documentation (Pumariega, Rothe, & Pumariega, 2005). Once these individuals are finally resettled, they face a myriad of new challenges post-migration. These stressors include: educational and employment barriers, poorly performing schools, overcrowded and segregated housing, high neighborhood crime rates, discrimination and pressure to acculturate (Pumariega, Rothe, & Pumariega, 2005). They also include culture shock, language barriers (Berman, Giron & Marroquin, 2006), disrupted social support systems (Guruge, Khanlou, & Gastaldo, 2009), shifting roles and responsibilities, heavy external and domestic work burdens, and sexist stereotypes (Goodkind & Deacon, 2004). Thus, it can be said refugee and immigrant women are "triply marginalized due to their economic, racial/ethnic, and gender status" (Goodkind & Deacon, 2004, p. 724).

These substantial stressors, as well as the trauma and deprivation they may have faced in their countries of origin, as well as the dangers of the migration process itself, place refugees and immigrants at a significant risk for experiencing mental health problems (Keyes, 2000 as cited in Pumariega, Rothe, & Pumariega, 2005). Unfortunately, adequate progress has not yet been made in terms of developing effective programs to meet the unique needs of these individuals. This is especially true for refugee women (Berman, Giron & Marroquin, 2006, p 34).

Immigrants, Refugees and Gender-based Violence

Societies around the world possess elements of gender inequality that put women at risk for experiencing interpersonal violence. In more peaceful times, social constraints such as family norms serve as protective factors, however propensities towards committing acts of violence against women are heightened during emergencies as many protective factors are eliminated (Benjamin & Murchison, 2004). Sadly, the challenges refugee and immigrant women face are what has been aptly referred to as "intersecting forms of intimate and structural violence" (Parson, 2010, p. 897). For example, they may face structural violence in their countries of origin, such as rape during war, as well as in their countries of resettlement, in terms of discrimination against women of color. Meanwhile, they may simultaneously face intimate forms of gender-based violence, such as marital rape, in the pre- and post-migration contexts. Attributing the impact on women's health, including mental and reproductive health, to one form of violence is particularly complicated as many forms of violence against women happen concurrently (Hynes & Cardozo, 2000) and also go unreported (Benjamin & Murchison, 2004).

A report by Save the Children describes the environmental factors that put refugee and some immigrant women at elevated risk levels. They state, “in times of crisis brought on by war, forced displacement, or natural disasters, incidents of gender-based violence tend to increase due to social upheaval and mobility, disruption of traditional social protections, changes in gender roles, and widespread vulnerabilities” (Benjamin & Murchison, 2004, p. 5). The breakdown of social systems, fractured family and social support networks, as well as overcrowded living environments play a large role (March, et al., 2006). Furthermore, refugee and immigrant women are at risk from experiencing violence, including sexual violence, at the hand of many individuals. In their countries of origin, especially in the context of war, they may be at highest risk for experience violence perpetrated by strangers, including soldiers and police (Hynes & Cardozo, 2000).

During the migration process, they may be at highest risk from others also experiencing the stressors of forced migration, such as other refugees in crowded camps, or residents of the country of their temporary settlement (Hynes & Cardozo, 2000). Even though women and children make up the majority of displaced populations (up to 80%), they are also the poorest and most vulnerable, moreover, systems of assistance are geared towards men as the traditional heads of the household (Benjamin & Murchison, 2004). Women are more likely to be illiterate and lack key information on issues such as their rights and how to navigate the humanitarian assistance system to obtain benefits (Benjamin & Murchison, 2004). In these times, women may have to take on traditionally male roles, due to the absence of male family members, and leave the relative safety of

more protected areas unaccompanied only to face groups of men engaging in unsanctioned activities (Benjamin & Murchison, 2004).

Finally, post-settlement, refugee and immigrant women may find themselves at risk for experiencing violence from an intimate partner without the benefit of their traditional support systems (Westhoff, et al., 2008). Particular risk factors for experiencing intimate partner violence upon resettlement include: pre-migration violence and marital gender inequality, as well as shifts in social support and socioeconomic status (Guruge, Khanlou, & Gastaldo, 2009). These women are also at an increased risk for victimization due to factors including: isolation, language barriers, traditional gender roles, lack of legal documentation, and economic insecurity (Raj & Silverman, 2002). Furthermore, institutional barriers, such as immigration, social welfare policies, and cultural insensitivity make it difficult for them to seek services once they are needed (Dasgupta, 2005).

Unfortunately, despite these numerous risk factors, there is a dearth of research and scholarly literature on the topic of gender-based violence, particularly intimate partner violence, in refugee and immigrant communities (Family Violence Prevention Fund [FVPF] & Robert Wood Johnson Foundation [RWJF], 2009). In fact, the research we do have is contradictory as some studies suggest that intimate partner violence rates are similar or even lower among immigrant and refugee communities (FVPF& RWJF, 2009). However, the lack of nationwide prevalence studies focusing on immigrant and refugee communities means that the evidence is largely inconclusive (FVPF& RWJF, 2009). Nonetheless, it is essential to note that immigrant and refugee women face unique

risk factors which must be explored in an effort to remedy the myriad of challenges these women face in accessing culturally appropriate services. It is also important to recognize that "gender-based violence undermines not only the safety, dignity, overall health status, and human rights of the millions of individuals who experience it, but also the public health, economic stability, and security of nations" (United States Agency International Development, 2012, p. 7).

Immigrants, Refugees and Gender Inequality

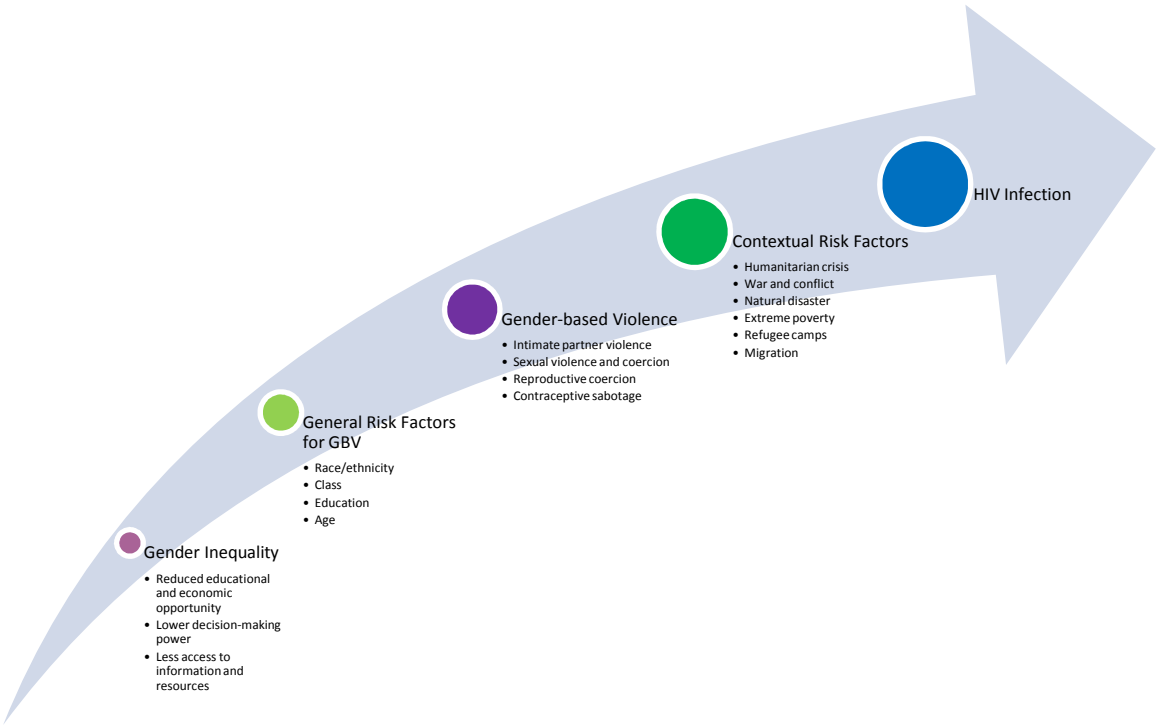
Levels of gender inequality also put refugee and immigrant women at significant risk. In fact, the United Nations Development Fund for Women (n.d.) has noted that efforts to reduce gender inequality actually lead to a decrease in incidents of gender-based violence. Furthermore, studies have found an association between gender inequitable views and sexual violence. A study conducted in South Africa found that men who held less equitable views on women were: more likely to believe various rape myths, have more sex partners, act violently towards women, and possess greater feelings of sexual entitlement (Jewkes, Sikweyiya, Morrell, & Dunkle, 2011).

The Population Reference Bureau (PRB) (2011) published a report on the status of women and girls in 2011 to examine gender inequality. The study found that many women, as well as men held beliefs that support gender inequality. The report found that gender inequality is an issue of major concern for many sending countries in Africa. For example, in Uganda 40% of women agree that men are justified in physically abusing their spouse, if their spouse argues with them. That is compared to 36% of men (PRB, 2011). In addition, 31% of Ugandan women also believe that men are justified in

physically abusing their wives, if the wife refuses to have sexual intercourse with them. Interestingly, a lesser number, 19%, of men agree (PRB, 2011). The report also highlights gender inequality in terms of men making the majority of household decisions. For example, in Malawi in 2004, the following percentages of decisions are made by men: 70% of decisions regarding his wife's health care; 80% of decisions regarding large household purchases; 65% of decisions regarding daily household purchases; and 38% of decisions regarding making family visits (PRB, 2011).

Figure 1 below provides a visual representation of the escalating risk levels immigrant women face in terms of contracting HIV. Issues related to gender inequality, such as reduced educational and economic opportunities, lower decision-making power and lack of access to information and resources, put women at risk for experiencing gender-based violence, as well as HIV. Next, general risk factors, such as race/ethnicity, class, education and age, enhance women's vulnerability for experiencing gender-based violence, including intimate partner and sexual violence. Finally, contextual factors, such as humanitarian crises, extreme poverty and migration, further compound women's risk for contracting HIV.

Figure 1: Conceptual Framework: Factors Leading to Escalated Risk for African Immigrant Women Contracting HIV



Immigrants, Refugees and Reproductive Health

Interestingly, the United Nations Development Fund for Women (n.d.) has found that nations working to uphold and protect the reproductive health of their female population experience fewer incidents of gender-based violence. Nonetheless, a review of the international literature highlights the urgent need to address reproductive health issues at the global level. The findings are reflected in the following quote:

> every year, more than 120 million couples have an unmet need for contraception, 80 million women have unintended pregnancies (45 million of which end in

> abortion), more than half a million women die from complications associated with pregnancy, childbirth and the postpartum period, and 340 million people acquire new gonorrhea, syphilis, chlamydia, or trichommonas infections (Glasier, et al., 2006, p. 1595).

This situation is even more severe for refugee and immigrant women because in situations of natural disasters and forced migration, reproductive health is often neglected (Westhoff, et al., 2008). In any humanitarian crisis, "every aspect of a woman's life is impacted, including her sexual activity and decision-making about her sexual health" (Westhoff, et al., 2008, p. 96). Furthermore, sexual violence is a major threat during the migration process, as is sexual exploitation and pressure to engage in coping strategies such as survival sex (Westhoff, et al., 2008). This puts women at risk for unintended pregnancies, as well as contracting STIs (Benjamin & Murchison, 2004).

Immigrants, Refugees and HIV

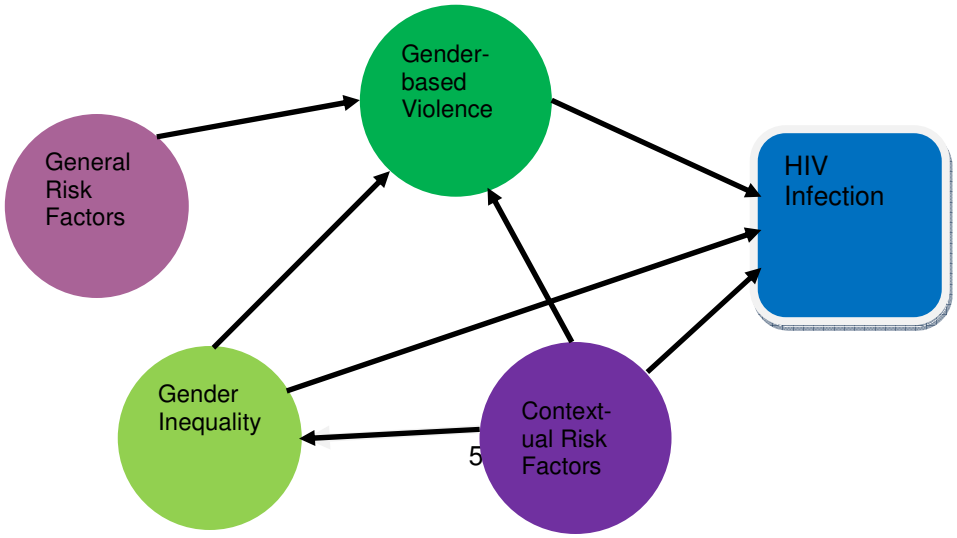
In terms of the global HIV epidemic, the United Nations General Assembly (2001) declared in its missile *Declaration of Commitment on HIV/AIDS* that*:*

> The global HIV/AIDS epidemic through its devastating scale and impact, constitutes a global emergency and one of the most formidable challenges to human life and dignity, as well as to the effective enjoyment of human rights, which undermines social and economic development through the world and affects all levels of society-national, community, family and individual (p. 6).

Humanitarian crises, including natural disasters, but particularly armed conflict and war, create situations of heightened risk for the spread of HIV (Benjamin & Murchison, 2004; Westhoff, et al., 2008). The increased transmission of HIV results mainly from higher rates of gender-based violence, particularly sexual violence, and constrained sexual decision-making (Kenny, Carballo & Bergmann, 2010; UNFPA, 2010; Westhoff, et al., 2008). In fact, in some situations the widespread rape of women is used as a tactic of war (examples include Bosnia, Congo, and Rwanda) (UNFPA, 2010).

Figure 2 below is a visual representation of the risk factors for contracting HIV that have been reviewed in the previous sections. The figure highlights that gender inequality heightens women's risk for experiencing gender-based violence, as well as contracting HIV. Other general risk factors, such as race/ethnicity, class, education and age, enhance women's vulnerability for experiencing gender-based violence, including intimate partner and sexual violence. Finally, contextual factors, such as humanitarian crises, extreme poverty and migration, increase women's risk for experiencing gender inequality, gender-based violence and contracting HIV.

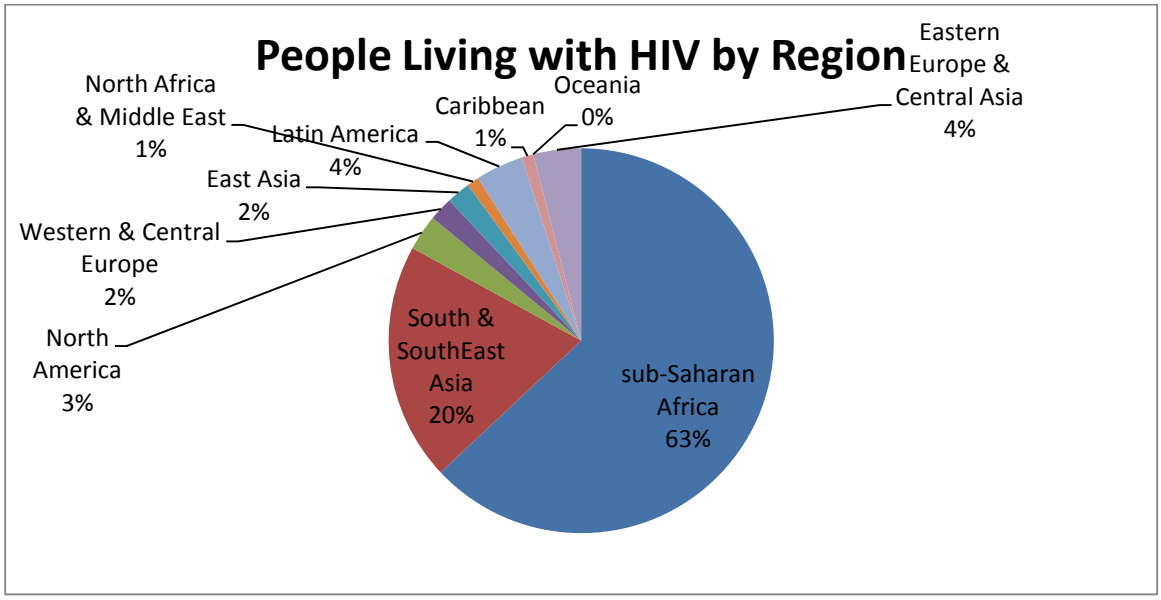
Figure 2: The Intersectional Role of Gender-based Violence, Gender Inequality and Contextual Risk Factors in HIV Infection



Sub-Saharan Africa

The *Declaration of Commitment on HIV/AIDS* goes on to state that sub-Saharan Africa is the region most deeply impacted by the HIV/AIDS epidemic in the world and that the situation is so dire that it is reducing life expectancies, threatening economic development, and even leading to political instability (United Nations General Assembly, 2001). Over 60% of HIV+ individuals (25.8 million) live in sub-Saharan Africa, even though it only constitutes approximately 10% of the world's population (UNAIDS, 2005). This includes approximately three-fourths of HIV+ women worldwide (Prasad, 2008).

Figure 3: People Living with HIV by Region (Ramachandran, Subbiah, & Ravishankar, 2008, p. 310)



The *Declaration of Commitment on HIV/AIDS* recognizes the heavy burden women carry as they are disproportionately affected by the epidemic, particularly African women (Dunkle, et al., 2004).Women often have less information about HIV and face

socioeconomic risk factors, such as poverty (Prasad, 2008). A majority (over 55%) of HIV+ adults in sub-Saharan Africa are women (UNAIDS, 2000 as cited in Benjamin & Murchison, 2004). In fact, in some areas of the region, adolescent girls have prevalence rates five times than those of adolescent males (UNICEF, 2003 as cited in Benjamin & Murchison, 2004). It is not completely understood why HIV rates are so high in sub-Saharan African, however, according to UNAIDS, some of the main factors include "poverty, social instability, gender inequality, patterns of sexual networking, sexual violence and other STIs…lack of male circumcision, high mobility, rapid urbanization modernization, and ineffective leadership during critical period in the epidemic spread (UNAIDS, as cited in Ramachandran, Subbiah, & Ravishankar, 2008, p. 298).

The United Nations declaration also states that gender equality is essential to reducing infection rates among women and that significant effort must be made to safeguard the human rights of women and increase their sexual decision-making and autonomy so they can protect themselves from HIV infection (United Nations General Assembly, 2001). However, "just as it is inaccurate to speak of a single 'African' AIDS epidemic, national-level HIV prevalence data can sometimes prompt incomplete pictures of the actual state of affairs" as there is a large variance in infection rates by community due to contextual factors (UNAIDS, 2005, p. 17). Furthermore, "although most women affected by HIV/AIDS are in sub-Saharan Africa, almost all existing research on violence and women's HIV risk comes from the USA" (Dunkle, et al., 2004, p. 1415). This large disparity is a serious limitation of the currently available research as it is unreasonable to

believe that research findings can be accurately applied in across all cultural and social settings (Dunkle, et al., 2004).

Gender-based Violence and HIV Internationally

It is patriarchal norms, which are existent in virtually all cultures, which support the intersection of violence against women, gender inequality and HIV (WHO, 2010). For example, gender norms dictate that women should be sexually submissive, innocent and accepting of their partners' risky sexual behavior (WHO, 2010). Research from around the world has firmly established a link between gender-based violence and HIV, in fact "women living with HIV are more likely to have experienced violence and women who have experienced violence are more likely to have HIV" (WHO, 2010, p. 1). Testing positive for HIV also puts women at increased risk of experiencing violence at the hand of an intimate partner (UNFPA, 2010). Thus, efforts to prevent the spread of HIV must include techniques to reduce violence against women and improve gender equality (WHO, 2010). The World Health Organization (2010) concludes that:

> The relationship between VAW and HIV risk is complex, and involves multiple pathways, in which violence serves both as a driver of the epidemic, and at times a consequence of being HIV positive. Rape is one potential cause of direct infection with HIV through violence for some women. However, the primary burden of HIV risk from VAW and gender inequality arises through longer-acting indirect risk pathways. These involve both chronically abusive relationships where women are repeatedly exposed to the same perpetrator, as well as the long-

term consequences of violence for women who have experienced prior, but not necessarily ongoing, exposure to violence (p. 1).

Gender Inequality and HIV Internationally

Gender inequality is also reflected in the high fertility rates in sub-Saharan Africa, as well as early marriage rates (Population Reference Bureau, 2011). Moreover, not surprisingly, research has found that levels of gender inequality are related to risk of HIV infection in sub-Saharan Africa (Tsai & Subramanian, 2011). Situations of inequality dictate women's behavior in their intimate relationships. Therefore, we see much higher rates of unplanned pregnancies, as well as STI and HIV infection rates among women who are not at liberty to decline sexual relations with their intimate partner (Population Reference Bureau, 2011). A research study examining data from 22 African nations used responses to hypothetical situations involving intimate partner violence to measure gender inequality, which it referred to as the "proximate context of gender-unequal norms" (Tsai & Subramanian, 2011, p. 00). The study found that condom use was negatively associated with higher levels of agreement with gender unequal norms (Tsai & Subramanian, 2011).

A separate study of 2,049 individuals from Botswana and Swaziland found that HIV-related risk factors, such as rape, unsafe sex, and sexually coercive behavior was associated with male belief in gender inequality (Shannon, et al., 2012). The researchers (Shannon, et al., 2012) succinctly explain women's increased risk for contracting HIV by explaining:

> More specifically, our study demonstrates that higher adherence to gender inequality norms are associated with elevated women's risk of HIV acquisition by reducing women's control over their sexual and reproductive health (including barrier contraceptives, decisions on when/how often to have sex), and simultaneously increasing economic dependence on men through intergenerational sex with older men and transactional sex (p.7).

In terms of prevention and intervention, Dr. Jonathan Mann, the former Director of the HIV/AIDS Unit at the Centers for Disease Control and Prevention aptly summarized the situation this way:

> The central problem of HIV in women can't be solved with posters, information campaigns or condom distribution. The central issue isn't technological or biological; it is the inferior status or role of women. To the extent that, when women's human rights and dignity are not respected, society creates and favors their vulnerability to AIDS (as cited by Benjamin & Murchison, 2004, p. 16).

Behavior of Male Perpetrators

Often women's risk for contracting HIV is linked to the behavior of their male partners. A longitudinal study of 1,099 South African women found an association between HIV and intimate partner violence and unequal gender norms in their intimate partnerships (Jewkes, Dunkle, Nduna, & Shai, 2010). Similarly, a study of 1,366 women seeking prenatal care in South Africa found that both intimate partner violence and "high levels of male control in a woman's current relationship" were associated with a positive

HIV status (Dunkle, et al., 2004, p. 1415). The researchers even went so far as to suggest that men who abuse their intimate partners are more likely to engage in high risk sexual activity and, thus, be HIV+ (Dunkle, et al., 2004). Research by the WHO (2010) also supports this claim by highlighting that abusive men do indeed tend to engage in more risky sexual behavior that put them at risk for contracting HIV. These behaviors include, having concurrent sex partners, abusing substances (WHO, 2010) and refusing to use condoms with their multiple partners (UNFPA, 2010).

Modes of Transmission

Women are at risk from various modes of transmission. These include: unsafe coercive sex with intimate partners, direct transmission through rape, lack of immediate medical care including post-exposure prophylaxis following an incident of rape, as well as continued violence after discovery of her HIV+ status (Ellsberg & Betron, n.d.). Sadly, the sexual violence that often accompanies periods of war and conflict, such as the Rwandan genocide, have indeed led to high HIV prevalence rates (Benjamin & Murchison, 2004). The unique methods of HIV transmission due to rape in times of war include: forceful, violent rape resulting in vaginal tissue damage; contracting STIs which heighten one's risk for HIV; and exposure to populations with high HIV rates, such as soldiers (Benjamin & Murchison, 2004).

Summary

In addition to informing our understanding of the manner in which gender inequality heightens women's risk for experiencing gender-based violence, as well as contracting HIV, the previous section highlighted key contextual factors related to

international migration, such as armed conflict, extreme poverty and shifts in traditional gender roles upon resettlement. These factors increase women's risk for experiencing gender inequality, gender-based violence and contracting HIV. The convergence of these risk factors is particularly troubling in sub-Saharan Africa, where women are disproportionately affected in the region most deeply impacted by the global HIV/AIDS epidemic (United Nations General Assembly, 2001). Finally, this section points to a gap in the scholarly literature of culturally appropriate research on the role gender-based violence plays on HIV risk for women residing in or immigrating from sub-Saharan Africa (Dunkle, et al., 2004).

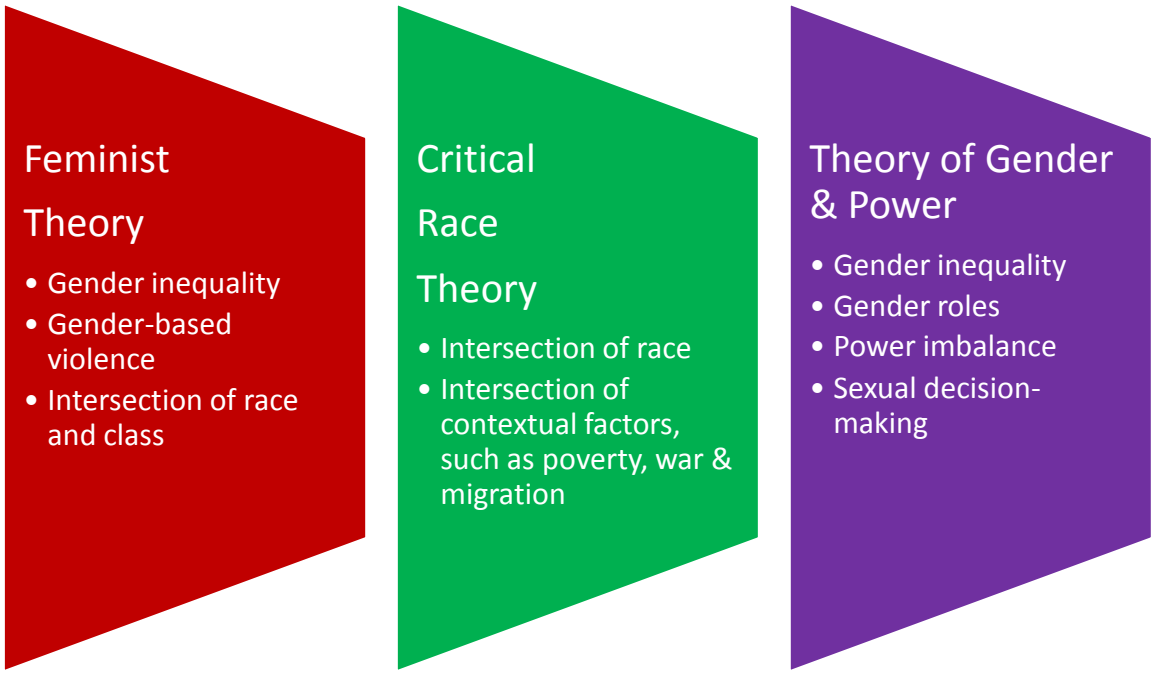
THEORETICAL FRAMEWORK

The contextual factors discussed in the literature review, as well as the understanding of their complex interplay in the lives of immigrant women, were informed by this study's theoretical framework. Many theorists and researchers have grappled with determining the causes of gender-based violence and gender inequality, as well as the negative consequences of these forms of oppression against women. This study utilizes Feminist Theory, Critical Race Theory and the Theory of Gender and Power to guide the exploration of the social and economic factors (such as race and class) related to one's vulnerability for experiencing violent victimization, as well as various negative reproductive health outcomes, such as HIV infection. Each of these theories offer distinct guidance in thinking about the phenomena being examined, as well as offer key insights into the research process, including the researcher's relationship to the participants, the kinds of questions to ask and how to interpret data (Reeves, Albert,

Kuper & Hodges, 2008). An exploration of Feminist Theory and Critical Race Theory sheds light on the social, economic, historical and political context surrounding violence against women. The Theory of Gender and Power illuminates how gendered power dynamics play out within intimate relationships. These theories highlight that gender-based violence and gender inequality must be understood within a framework of multiple oppressions that converge to make women vulnerable to victimization (Collins, 2004).

Feminist Theory and Critical Race Theory in particular emphasize that in order to learn more about the oppression of diverse women, it is essential to place previously marginalized groups in the center of the analysis. Thus, this study focuses on giving voice to the experiences of multiply marginalized women, namely HIV+ African immigrant women. Doing so will provide a clearer and fuller understanding of oppression and its impact on diverse women. Furthermore, these theories: respect the multiple identities of women; call attention to issues of race, class, and gender and their impact on reproductive and sexual health; question social norms which promote violence and inequality; and help broaden our understanding of these concepts in order to reflect the lived experiences of diverse women. Figure 4 below provides a summary of the key unique contributions from each of the theories that make up the theoretic framework for this dissertation study. These contributions inspired the line of research inquiry used to develop the study's research questions, as well as interview questions.

Figure 4: Guiding Theoretical Framework



Feminist Theory

Feminist thought sprung from a demand for equality and movement away from patriarchy, and grew to highlight many social issues, such as gender-based violence (Hardcastle, Powers, & Wencour, 2004). Feminism, and therefore Feminist Theory, is a broad term which is difficult to define (Ford, 2008). Nonetheless, feminists seek to overcome oppression, which is the domination of one group over another, in this case, men over women (Hardcastle, et al., 2004). It has been classified as a critical theory which challenges social norms, assumptions and false dichotomies (Hardcastle, et al., 2004). Feminist Theory has also been classified as a radical theory focused on overcoming structural inequalities through consciousness raising activities which

acknowledge oppressive structures and institutions and try to develop ways of creating change (Payne, 1997).

A main concept addressed by feminism is patriarchy, a social structure in which men enjoy social privileges and dominate society (Hardcastle, et al., 2004) and women occupy a marginalized status. Another important concept is power. Feminists view power differently than mainstream society which views it as the strength and force necessary to get what you want (Hardcastle, et al., 2004). Instead, feminism views power in terms of the ability to create change (Hardcastle, et al., 2004). Feminists do not see power as finite, but instead as something that can be shared (Wingwood & DiClemente, 2000). They also focus on the process of change, rather than solely the end result of their effort (Wingwood & DiClemente, 2000). In feminist thought, the concept of empowerment provides a framework to create change and facilitate self-determination in the lives of women (Busch & Valentine, 2000).

Feminist Theory has been the foundation of the anti-violence against women movement (McPhail, et al., 2007). It asserts that gender is socially-constructed (Ford, 2008) and provides a useful lens to gain additional insight into the dynamics surrounding gender-based violence and gender inequality. Mahmood (2005) offers an effective synopsis of feminism, arguing that it recognizes the gender-bias inherent in society and, therefore, has the means to locate and explain the position of women, as well as provide direction for social change through self-empowerment. A feminist perspective illustrates that sexuality needs to be understood in the context of significant gender inequalities, as well as racial and class inequalities (Fields, 2008). Thus, Feminist Theory helps us

understand how multiple forms of oppression intersect to make women vulnerable to violence (Collins, 2000). It is through the acknowledgment of gross inequalities that we can promote healthy relationships, free from violence and coercion, as well as provide survivors with a voice through which to express their pain and heal from their experiences.

Feminist Theory teaches that practitioners must value the lived experiences of individuals (Lengermann & Niebrugge, 2007), therefore, they must seek to learn about and validate the experiences of diverse women and allow their voices to be heard (Lengermann & Niebrugge, 2007). Thus, Feminist Theory is the impetus for this study which seeks to give voice to the experiences of HIV+ African immigrant women, who have largely been invisible in social science research. Feminist Theory promotes the use of personal narratives as a means to challenge patriarchal norms and other forms of oppression (Chase, 2005). Feminist Theory also provides guidance as to how researchers should position themselves in relation to their participants, suggesting that they should be equal partners in the research process, with the researcher serving primarily as a listener and interpreter (Chase, 2005).

Black Feminist Theory

Black Feminist Theory developed, in part, due to the marginalization of women of color in the feminist movement (Ford, 2008). It began as a means of understanding the impact of both race and sex inequalities (Payne, 1997). Although by no means limited to African American women, Black Feminist Theory began by recognizing that African American women occupy a unique standpoint positioned by an oppressive social

hierarchy and that this standpoint shifts based on historical and social changes (Few, 2007). Black Feminist Theory seeks to examine intersecting forms of oppression and empower women to overcome them despite the burden of inequality they face (Collins, 2000). The application of Black Feminist Theory is not limited to African American women, but is applicable to all multiply marginalized women. Collins (1998) teaches that the theory provides a universal perspective by building a theoretical framework informed by the unique lived experiences of women of color, while focusing on dismantling a variety of social injustices. The women in this study are HIV+ African immigrants. They face marginalization based on their gender, race and disease status. Their status as immigrants also puts them at risk for stigma and isolation due to social, cultural and linguistic differences. Thus, it is important to understand their positionality in a hierarchical society, as well as the intersection of multiple forms of oppression in their lives.

Black Feminist Theory is useful in situating the phenomenon of gender-based violence and gender inequality in the broader society. It can also build understanding in terms of how to conduct feminist research by allowing women to define their own experiences. Black Feminist Theory points to the significance of language. bell hooks and Patricia Hill Collins, in particular, explored the significance of and meaning behind language; asserting that it impacts one's identity and, therefore, it is essential that women have the freedom and ability to define themselves (Few, 2007). As immigrants, the women in this study have presumably faced a number of life challenges and endured a tremendous amount of social and cultural change. Some may also have experienced

gender-based and sexual violence. It is important for survivors to define their own experiences (Rountree & Mulvaney, 2008) and to claim their own identities instead of taking on the labels that others assign to them. This is especially important when conducting cross-cultural research with multiply marginalized women. Thus, as informed by Black Feminist Theory, instead of being bound to strict definitions, this study seeks to gather information on how the participants view, understand and label their own experiences.

Critical Race Theory

Critical Race Theory is a critical theory which examines the impact of structural issues on the perpetuation of racism (Hatch, 2007); a form of oppression that created, and still reproduces, the unequal structures that make up our society today. Critical Race Theory is grounded in African American, Latino/Latina, and Native American critical social thought and is focused on the institutionalization of racism and its use as a tool of oppression (Parker & Lynn, 2002). This theory understands that, like gender, race is a social construction that must be deconstructed in order to be fully understood (Parker & Lynn, 2002). Critical race theorists examine structural determinism to understand the impact of institutionalized racism, unequal power structures and intersecting forms of oppression affecting marginalized communities (Delgado & Stefancic, 1993; Hatch, 2007).

Critical Race Theory is built on the lived experiences of individuals (Hatch, 2007). The theory also recognizes the power of personal testimony (Hatch, 2007). Thus, Critical Race Theory is useful in relation to research with multiply marginalized women

because it privileges the stories and testimonies of women and validates them as their true lived experiences. Thus, storytelling is an important aspect of Critical Race Theory in that it challenges the information the dominant group puts forth as the truth (Delgado & Stefancic, 1993). Furthermore, by focusing on the lived experiences of individuals, it takes their social context into account and highlights their positionality in society (Parker & Lynn, 2002). Thus, Critical Race Theory has important implications for conducting cross-cultural research and points towards the use of narrative analysis and the creation of a "mutually accomplished story" out of the partnership between researcher and participant (Fontana & Frey, 2005, p. 714).

Standpoint

Informed by Feminist Theory and Critical Race Theory, the concept of standpoint is helpful in that it illuminates the social hierarchy in which researchers and participants live and operate. Smith (1992) suggests that the concept of standpoint is concerned with the real lived experiences of women and recognizes that in an unjust world, groups experience varying levels of autonomy. Furthermore, their comparative power can only be understood within the context of strict hierarchical relationships with other groups (Smith, 1992). Nonetheless, it is essential not to overemphasize homogeneity within groups of women (Collins, 1998), as has been done traditionally in the past (The Latina Feminist Group, 2001). Thus, this view of positionality should be balanced with González-López's (2005) concept of ***"regional patriarchies"*** in order to caution against overgeneralizations and recognize that the nature and impact of patriarchy is not uniform across a society. Instead, oppression is fluid and varies across time and space. Thus, only

women's lived experiences can reveal the true dynamics of their unique social context. As a white, middle class US citizen, it is essential that I remain truly open to exploring the experience of research participants as they describe it, as opposed to making assumptions about their lives based on their country of origin or migration experiences.

Intersectionality

The concept of intersectionality is also important because it builds on and challenges the concept of standpoint by placing less emphasis on group identity, focusing instead on individuality and "…the ability of social phenomena such as race, class and gender to mutually construct one another" (Collins, 1998, p. 205). Intersectionality argues that although marginalized individuals all experience oppression, we cannot assume that their experiences are similar or equivalent (Collins, 1998). Because individuals embody a number of identities, efforts to end gender-based violence and gender inequality must address multiple forms of oppression, such as racism and classism (Davis, 2003).

Intersectionality examines socially constructed dimensions of identity that define power and control and intersect to create a complex system of domination (Crenshaw, 1991). Thanks to the contribution of intersectionality, we can see the struggle faced by many women, such as low-income immigrant women of color, who possess multiple marginalized identities. Intersectionality also speaks to the complexity of women's lived experiences, as the influence and effects of the multiple and intersecting forms of oppression cannot be disentangled. Thus, the concept of intersectionality points to the need for complex, holistic approaches to ending gender discrimination and violence, as

well as mitigating the negative health impacts multiple forms of oppression can lead to in women.

Theory of Gender and Power

Robert Connell is credited for creating the Theory of Gender and Power in the late 1980s which is an outgrowth of the feminist movement (Wingwood & DiClemente, 2000). The critical theory states that gender roles, as well as cultural and social norms, are polarized and reinforced by social structures and inequalities (Wingwood & DiClemente, 2000). The theory argues that the division of labor based on gender promotes inequality and dependency, as many of the tasks assigned to women are unpaid, such as housework, and slow women's career development. Many of the studies that utilize this theory focus on the transmission of STIs (predominantly HIV). The theory, which focuses on the public health field, developed as an alternative to other theories on the transmission of HIV which focused too heavily on individual behaviors. This theory, which examines gender-based domination and power imbalances, offers an understanding of structural issues which constrain personal decisions and, thus increase risk of contracting STIs (Wingwood & DiClemente, 2000).

Wingwood and DiClemente (2000) argue that it is the gender inequality which women face that generates risk factors that can lead to negative health outcomes. Thus, they argue structural issues in communities make women more dependent on men. As the gap in power between the genders increases, women are exposed to more risk factors and tend to experience more health-related problems (Wingwood & DiClemente, 2000). This dynamic is important to understanding which social contexts place women at additional

risk for experiencing gender-based violence, as well as suffering the potential impact on their reproductive, physical and mental health.

Pulerwitz, Gortmaker, and DeJong (2000) drew on the Theory of Gender and Power to examine the power imbalance between men and women and its impact on women's ability to make decisions regarding their sexuality, such as the ability to negotiate safe sex. They found that as one's power within a relationship increased, their risk of experiencing sexual and physical violence decreased and their ability to consistently use condoms increased. Thus, the importance of addressing gender power inequalities in order to protect women's sexual and reproductive health and rights is clear.

The Theory of Gender and Power also recognizes the many social norms governing women's sexuality and gender roles and that the strict performance of these norms can lead to negative health outcomes (e.g., restrictions on the use of condoms or other forms of birth control) (Wingwood & DiClemente, 2000). For example, socioeconomic factors, such as being a person of color, being young, living in poverty, and having a lack of education and employment put women at risk for contracting an STI (Wingwood & DiClemente, 2000). Other risk factors related to relationships highlighted by the authors include: experiencing sexual and physical violence, having a partner with risky sexual behavior, lacking knowledge about and confidence in condom negotiations, discouraging influence of family members, fear of the medical system, and traditional religious beliefs (Wingwood & DiClemente, 2000). All these factors work to reinforce the health risks experienced by women. These risk factors very closely resemble those associated with experiencing gender-based violence. The Theory of Gender and Power

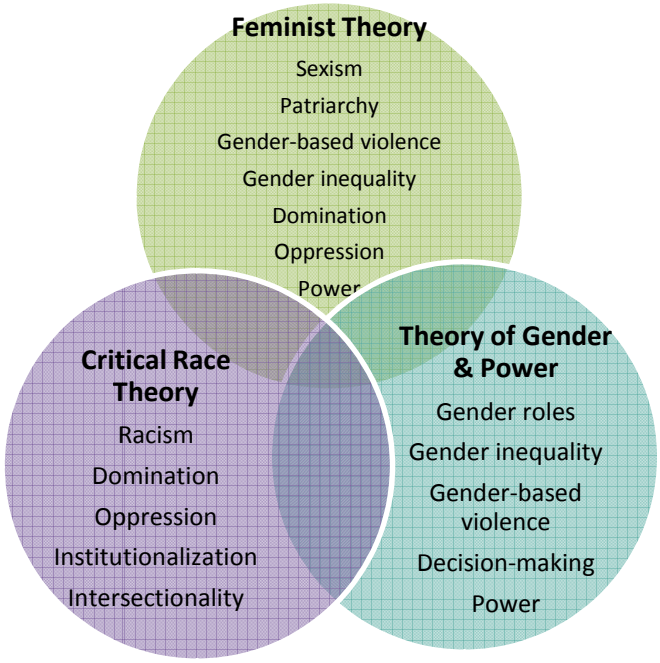
recognizes that individual choices are constrained by power inequalities within intimate relationships. Hence, it offers significant insights into the key concepts that should be probed when researching gender-based violence, gender inequality and HIV. These concepts include sexual decision-making, power imbalances, autonomy, and differentiated gender roles (Wingwood & DiClemente, 2000).

Summary of Theoretical Framework

This study utilizes Feminist Theory, Critical Race Theory and the Theory of Gender and Power as a framework for contextualizing the experiences of the women participating in the study. As critical theories, they shed light on the social, economic, historical and political context surrounding violence against women. While Feminist Theory and Critical Race Theory are grand theories, the Theory of Gender and Power is a micro level theory which provides insight into the manner in which inequalities play out in intimate relationships. The concept of standpoint teaches the importance of recognizing an individual's position in the social hierarchy, while the concept of intersectionality highlights that gender-based violence and gender inequality must be understood within a framework of multiple oppressions that converge to make women vulnerable to victimization (Collins, 2004). Thus, in offering direction in terms of how to explain the causes and influences of these phenomena, these three main theories also provide insight in terms of how to potentially overcome these social issues (Reeves, Albert, Kuper & Hodges, 2008). Lastly, these theories point to the importance of testimony based on one's lived experience and hence theoretically support the use of narrative analysis as the appropriate methodological choice for this study. Figure 5 below

shows how three theories overlap and work together to provide a coherent theoretic framework for this study.

Figure 5: Theoretic Framework



Chapter Three: Methodology

The purpose of this study was to explore the narratives of HIV+ African immigrant women to understand the role gender-based violence and gender inequality, as well as key contextual factors, such as poverty, have played in their constrained reproductive health choices and current disease status. This exploratory qualitative study was conducted through the use of in-depth interviews with English-speaking HIV+ African immigrant women over the age of 18 living in the southwestern United States. The primary research focus explored the women's narratives on the role of gender-based violence and gender inequality had on their HIV positive status. The secondary line of research inquiry sought to understand the influence contextual factors, such as poverty and the migration process, had on their risk for HIV infection. The study was designed to gain further insights into the contextual factors and personal experiences of HIV+ women with the goal of highlighting potential means of promoting women's reproductive health and, thereby, reducing the spread of HIV.

RESEARCH QUESTIONS

The study specifically addressed the following research questions:

1) Do HIV+ African immigrant women describe experiences of gender inequality as part of their life experiences?
2) Do HIV+ African immigrant women describe encounters of gender based violence, including sexual violence, as part of their life experiences?
3) How do HIV+ African immigrant women describe their sexual decision-making?

4) Do HIV+ African immigrant women talk about contextual factors, such as poverty and migration, when they discuss their HIV status?
5) What do the stories of HIV+ African immigrant women teach us about HIV?

DEFINITIONS OF KEY CONCEPTS

There are a number of terms that are important to understand when exploring the role gender-based violence and gender inequality play on women's risk for HIV infection. Definitions for gender-based violence (including intimate partner violence and sexual violence), gender inequality and reproductive health are provided in the section below. These three terms were selected for definition as they have the greatest impact on the study's methodology and, thus, possible replication. Other terms, such as refugees and immigrants were defined briefly during the course of the literature review. Although these definitions provided a framework for exploring women's experiences, this study also sought to gain an understanding on how the study's research participants perceived and defined their own experiences.

Gender-Based Violence

The United Nations defines gender-based violence as:

> physical, mental or social abuse (including sexual violence) that is attempted or threatened, with some type of force (such as violence, threats, coercion, manipulation, deception, cultural expectations, weapons or economic circumstances) and is directed against a person because of his or her gender roles and expectations in a society or culture.…[and which] a person has no choice to

refuse or pursue other options without severe social, physical or psychological consequences (UNFPA, 2010, p. 8).

The term gender-based violence is often used as a synonym for violence against women. Thus, this study uses the terms interchangeably. However, it should be noted that the concept of gender-based violence can also be broadly defined to include violence perpetrated against individuals who do not fit into the socially constructed and narrowly prescribed definitions of femininity and masculinity, such as members of the LGBTQ community (O'Toole, et al., 2007). There are a variety of violent acts perpetrated against women that can be classified as gender-based violence. These acts can take place publically or privately (Benjamin & Murchison, 2004). Although men can also be affected, females are disproportionately impacted by gender-based violence as it works to deepen gender inequality (Benjamin & Murchison, 2004). In its *Multi-country Report on Women's Health and Domestic Violence,* the World Health Organization (2005) stated that "violence against women is both a consequence and a cause of gender inequality" (foreword). Watts and Zimmerman (2002) listed a number of the main manifestations of violence against women, including: intimate partner violence; sexual abuse by non-intimate partners; trafficking, forced prostitution, exploitation of labor, and debt bondage of women and girls; physical and sexual violence against prostitutes; sex selective abortion, female infanticide and the deliberate neglect of girls; and rape in war (p. 1232). ***For the purpose of this study, gender-based violence includes experiences of emotional, physical and sexual violence.***

Intimate Partner Violence

The World Health Organization asserted that intimate partner violence is one of the most prevalent types of gender-based violence across the world (Watts & Zimmerman, 2002). Broadly defined, intimate partner violence is generally considered to include "physical, sexual, or psychological violence between adults who were present and/or past sexual/intimate partners in heterosexual or homosexual relationships" (Thompson, et al., 2006, p. 448). The National Violence Against Women Survey (NVAWS), a highly respected, nationally representative survey, also incorporated stalking into the definition (Tjaden & Thoennes, 2000).

Sexual Violence

As previously mentioned, there are many forms of gender-based violence, however, this study places a particular focus on sexual violence as it is the form of gender-based violence that puts women at the most direct risk of contracting HIV. Definitions of sexual violence vary (Jewkes, et al., 2002) due to cultural influences (NSVRC, 2004). Traditionally, research on sexual violence has focused on rape. Rape is currently defined by the National Violence Against Women Survey as "forced vaginal, oral, and anal sex" (Tjaden & Thoennes, 2000, p. 13). However, this concept is not inclusive of the variety of women's experiences with sexual violence.

Feminism has worked to expand our understanding of sexual violence over time. Emerging discourse conceptualizes sexual violence as a continuum of unwanted sexual experiences (Cook, Gidycz, Koss, & Murphy, 2011). Scholars assert that this more recent understanding recognizes "less extreme forms of sexual assault and even more subtle

forms of sexual coercion" (Gavey, 2005, p. 6; see also Young & Maguire, 2003). Coercion has been referred to as "moral, psychological or intellectual force used to compel a person to engage in sexual intercourse against that person's will" (MacKinnon, 2003, p. 268). Thus, coercion is less related to force and more related to ignoring a partner's expression of their unwillingness to engage in sexual activity (Kelly & Erickson, 2007). Furthermore, coercion can be affected by social hierarchy, in terms of one person's position of dominance over the other as "autonomy in sex cannot exist without sex equality" (MacKinnon, 2003, p. 270).

This new concept of sexual violence as a continuum of unwanted sexual experience is more fluid and takes gray areas, such as consent, into account (Gavey, 2005). This expanded concept enables additional women to identify their unwanted sexual experiences as sexual violence, thus reducing the number of unacknowledged victims (Gavey, 2005). This step forward promises to shed light on the complex and nuanced social and contextual factors associated with sexual violence. ***Thus, for the purpose of this study, I defined sexual violence in broad terms, as a continuum of unwanted sexual experiences.***

Gender Inequality

Gender is "a primary characteristic by which we structure intimate relationships, divide labor, assign social value, and grant privilege" (O'Toole, et al., 2007, p. xii). Nonetheless, the term gender inequality is not easy to define. Again, it should be noted that the concept of gender inequality can be broadly defined in order to refer to inequality directed toward members of the LGBTQ community and/or individuals who are

perceived as challenging gender norms (O'Toole, et al., 2007). However, for the purposes of this study, gender inequality refers to inequality experienced by women in a patriarchal society.

Perhaps its' opposite, gender equality, is more concrete and easier to conceptualize. The United Nations Office of the Special Advisor on Gender Issues defines gender equality as "that stage of human social development at which the rights, responsibilities and opportunities of individuals will not be determined by the fact of being born male or female" (Lopez-Claros & Zahidi, 2005, p. 1). Gender inequality is often conceptualized as a "gap" between the genders on key human rights. A report published by the World Economic Forum argues that the gender gap can be measured in terms of five criteria: economic participation, economic opportunity, political empowerment, educational attainment, and health and well-being (Lopez-Claros & Zahidi, 2005). ***For the purpose of this study, gender inequality is conceptualized in terms of the social, cultural and economic inequalities women face and the role they play on women's vulnerability for contracting HIV. Factors of key interest include: family and community gender roles; household and relationship decision-making; and economic and educational opportunities.***

Reproductive Health

When studying the phenomenon of gender-based violence, it is important to understand the concepts of reproductive and sexual health. These concepts have been defined through the work of the 1994 International Conference on Population and Development in Cairo, Egypt (Glasier, Gulmezoglu, Schmid, Moreno & Van Look,

2006). There are many commonalities between the terms reproductive health and sexual health. They seek to reduce reproductive disorders, mitigate possible negative outcomes associated with sexual activity and promote healthy sexual relationships by attempting to overcome "gender discrimination, inequalities in access to health services, restrictive laws, sexual coercion, exploitation, and gender-based violence" (Glasier, et al., 2006, p. 1596). Although the two definitions have some redundancy, reproductive health, which includes sexual health under its umbrella, is defined as follows:

> Reproductive health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition is the right of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant (UN Report, as cited by (Glasier, et al., 2006, p. 1596).

Although the scholarly literature on reproductive health often focuses on contraception, pregnancy, and pregnancy outcomes, reproductive health care may include

the following among other services: contraceptive counseling, pregnancy testing, pap smear, pelvic exam, HIV counseling and testing, and STI testing and treatment (see Gazmararian, et al., 2000). Other discussions on reproductive health include sexual risk behavior, STI and HIV infection, unintended pregnancy and gynecological problems (see McMahon, Goodwin, & Stringer, 2000). Finally, according to the Programme of Action developed during the 1994 International Conference on Population and Development in Cairo, Egypt, reproductive health care services, include "…information, education and communication about reproductive health, including sexually transmitted diseases…diagnosis and treatment for sexually transmitted diseases and other reproductive tract infections…and referrals, education and counseling services for sexually transmitted diseases, including HIV/AIDS…" (World Youth Alliance, 2012, p. 4). ***For the purpose of this study, reproductive health is conceptualized broadly with a focus on sexual risk behavior, STI and HIV infection.***

RESEARCH METHOD AND DESIGN

Study Design

This project was conducted through the use of in-depth interviews with English-speaking HIV+ African immigrant women over the age of 18 living in the southwestern United States in stable mental and physical states. I conducted in-depth interviews with six women (n=6). A semi-structured interview schedule was used to facilitate discussion. The interview schedule (see Appendix A) addressed the women's family of origin, intimate partnerships, sexual decision-making, gender-based violence, gender inequality and HIV.

Description of the Organization

In order to undertake this dissertation research project, I developed a collaborative relationship with an AIDS service agency in the southwestern United States. The agency provides prevention services, as well as services to individuals infected and affected by HIV. The agency serves HIV+ immigrants from a variety of nations and is committed to continuing to enhance the services they provide to these individuals.

Criteria for Participation

I relied on the expertise of agency staff, mainly case managers, to assist me in identifying women who were open to participating in the study. Agency staff screened potential research subjects to ensure they met the following research eligibility criteria:

1. Over age 18
2. Proficient in speaking English (as determined by agency staff)
3. HIV+ (according to self-report)
4. Receiving (or have received) agency services
5. In a stable mental and physical state (as determined by agency staff)

Six women were recruited to participate in this study. The small sample size may be somewhat reflective of challenges related to recruiting this hard-to-reach and multiply marginalized population. In addition, fear of the stigma against HIV+ individuals in their community made some women decline participation in the study. Nonetheless, the lives and experiences of these six women adds to our knowledge about this area of inquiry. Research participants were immigrants from five different African nations. Even though

study participation was open to both refugees and immigrants, no refugees participated in the study. Chapter Four provides descriptions of the research participants.

Although this study sought to enhance our understanding of the influence of gender-based violence and inequality on risk for HIV infection, experience with gender-based violence was not an eligibility requirement for participating in the study. Thus, two of the six women had never experienced gender-based violence. Nonetheless, even the individuals that had not had direct experience themselves offered valuable information about their experiences living in a community with high rates of gender-based violence and its impact on perceptions of gender inequality.

Participant Recruitment

Agency case managers assisted the researcher in recruiting participants by individually informing potential participants of the study. Due to the experience, knowledge and expertise of agency staff, as well as their familiarity with the population they serve, potential research participants were only approached by agency staff to be asked whether they were interested in participating in the study. Agency staff used instructions provided by the researcher to recruit potential participants. Once the case manager determined a woman met the screening criteria and made a professional judgment and assessment about the readiness of the client to participate in the study, agency staff used the Oral Explanation of Research Study in order to review study-related information with the potential research participant and invite her to participate (See Appendix C). Case managers assured all possible research participants that their participation was completely voluntary and would not impact their relationship with the

agency nor access to community services. The women were also informed that they could change their mind about participating or stop the interview at any time without penalty. If a woman was interested in participating, a case manager either set up an interview themselves or provided me with the participant's first name (or pseudonym), phone number (if appropriate). This protocol was established to maintain the confidentiality and safety of potential research participants.

Agency staff made a professional judgment and assessment about the readiness of clients to participate in this study and only recruited individuals whose immediate emotional and physical health needs were being addressed. Case managers approached all potential research participants in order to ensure the potential participants did not feel coerced or pressured in any way to participate in the study. Any immediate issues that clients had were addressed prior to being recruited for this study and agency staff addressed any on-going case-related issues. In addition, agency staff served as a support and resource agency for participants in the event that during the research interview additional issues or distress arose. The contact information for the agency's chief administrative officer was provided to participants in case they felt uncomfortable discussing an issue with a staff member. In the end, six African immigrant women were recruited to participate in the study. Five nations were represented: Burundi, Cameroon, the Democratic Republic of the Congo, Malawi, and Zambia.

Human Subjects and Informed Consent Procedures

Due to the vulnerability of this population because of the stigma associated with HIV, as well as the risk of gender-based violence, a Waiver of Written Informed Consent

was obtained (See Appendix B). Therefore no participant signatures were obtained. Verbal consent was obtained and a form with contact information for the principal investigator, the service agency, and The University of Texas at Austin Institutional Review Board, was provided to the participants instead of a consent document. Prior to the interview, I carefully reviewed the purpose, risks and benefits of the study and answered any questions the individual had in order to ensure the details of the study were fully understood by the participant. Verbal consent was also obtained to audiotape the interviews.

Interview Format

Once the participant was screened and found eligible to participate in the study and had given their verbal consent, I conducted face-to-face interviews with research participants. Due to the in-depth information that needed to be collected for the purpose of a narrative, research participants were asked to participate in an approximately two hour interview. However, due to constraints such as transportation and child care, interviews averaged closer to an hour and a half each. A semi-structured interview schedule was used in order to learn more about the role gender-based violence and gender inequality played in their contracting HIV. The interviews also examined various contextual factors affecting the women's lives, as well as their family of origin, intimate partnerships, sexual decision-making, gender-based violence, gender inequality and HIV (See Appendix A). I provided participants with refreshments to ensure they were comfortable during the interview. Participants were welcome to take breaks during the

interview or ask to complete the rest of the interview the following day, however, all of the participants were able to finish the interview on the day they began it.

Compensation for Study Participants

Participants received $40 at the beginning of their interview as compensation for their time and expertise. It was determined that $40 was an appropriate incentive because it was thought that interviews might last over two hours. As the participants received their incentive at the beginning of the interview, they had the freedom of being able to choose to suspend or stop their interview at anytime, knowing they have already received compensation for the time and effort they contributed to the process, no matter how short. All of the participants were able to complete their interview.

Confidentiality

Securing Identifying Information

In most cases, the case manager set up the interviews without sharing the name and phone number of the individuals with me. In one case, the participant's first name and phone number was collected in order to schedule the interviews. No other identifying information was collected. Since the interviews took place at the service organization, addresses and other identifying information was not collected. Study-related materials were kept in a locked location. Participants were asked for permission to audiotape the interview. Each of the participants provided their consent to have their interview audio recorded. I also took brief field notes during the interview process. Following each interview, the name and phone number (if collected) of the participant was destroyed. Electronic transcript files were kept on a pass-word protected computer. Pseudonyms

were used for each of the research participants in the write-up of the findings in order to maintain their confidentiality.

Interview Location

Due to confidentiality concerns, the research participants were interviewed at the agency facility. A private location in the administrative office was identified so that only the participant and I were privy to the information discussed. Interviews were not conducted at the participants' homes in order to protect the participant and myself, should the participant be in an abusive relationship. This is also due to the stigma associated with HIV. Furthermore, it was important that the participant and I were able to have a private conversation in order to protect the participant's confidentiality.

Potential Risks and Benefits for Study Participants

Since the purpose of the study was to explore the role gender-based violence and gender-inequality play in risk for HIV infection, questions were asked about the participants' experiences with those issues. Another critical area in the interview guide were questions that explored the contextual factors in the participants' lives, as well as the women's family of origin, intimate partnerships, sexual decision-making, gender-based violence, gender inequality and HIV. Thus, the research participants were reminded that they do not have to answer any question that they do not feel comfortable in answering. They were also welcome to stop the interview at any time and it would not impact their relationships with the service agency or access to any community services. If the participant was not comfortable answering questions directly about gender-based violence or HIV contraction, for example, valuable information was still obtained by

exploring contextual factors such as marital relationships, economic situation, etc. Every effort was made to protect the confidentiality and well-being of each research participant.

Potential Risks

HIV+ individuals are a vulnerable population and subject to significant stigma. While only women receiving services from the agency were included in the study, the women may not have revealed their status to all groups (family members, friends, etc.). Thus, there was a potential risk for exposure of participant HIV status. However, due to the multiple precautions taken in the research protocol, these risks were remote and no greater than seeking services from the service agency. However, there were potential psychological risks involved in participating in the study. Potential risks included having an emotional response to the information they are sharing regarding their life experiences. At any point during the interview, if there was discomfort to the participant, she was free to stop the interview. In addition, as a researcher (a trained social worker with experience working with survivors of intimate partner and sexual violence) I developed a plan to talk with agency staff if any of the participants experienced any distress. The service agency is the main resource for HIV+ women in this area. Furthermore, this arrangement was thought to be the most effective as the women already have an established relationship with agency staff and have been receiving their assistance. Fortunately, this situation did not arise during the interview process.

Potential Benefits

There were no direct benefits for participating in this study. Overall, the potential benefit of conducting this study was a better understanding of the role gender-based

violence and gender inequality play in risk for HIV infection. Social service providers, researchers and funders can use this information to improve HIV prevention efforts.

DATA ANALYSIS

Theoretical Framework

In developing this research study, a theoretical framework based on Feminist Theory, Critical Race Theory and the Theory of Power and Gender was developed to inform the research questions, as well as the interview questions and the method of analysis. Feminist Theory teaches that practitioners must value the lived experiences of individuals (Lengermann & Niebrugge, 2007), therefore, they must seek to learn about and validate the experiences of diverse women and allow their voices to be heard (Lengermann & Niebrugge, 2007). Critical Race Theory's foundation is also built on the lived experiences of individuals (Hatch, 2007) and focuses on intersecting forms of oppression, as well as social context and positionality (Parker & Lynn, 2002). Critical Race Theory acknowledges that like gender, race is socially constructed (Hatch, 2007). These attributes were important in understanding the experiences of HIV+ African immigrant women as narrative analysis privileges the stories and testimonies of the marginalized and uses them to challenge the information the dominant group puts forth as the truth (Delgado & Stefancic, 1993). Finally, the Theory of Gender and Power illuminates how forces of oppression and inequality play out in the context of intimate partnerships and affect sexual decision-making and, thus, reproductive health.

Figure 6 below is a logic model outlining how this theoretical framework informed the study's research questions, interview questions and method of analysis.

Each theory is associated with corresponding research and interview questions. The research question regarding gender inequality is included twice in the logic model, as it is associated with both Feminist Theory and the Theory of Gender and Power. Similarly, the interview question on gender-inequality was repeated for the same reason. The specific contributions of each theory are explored in more detail in the section following the logic model.

Figure 6: Logic Model: Research Process

Theoretical Framework	Research Questions	Interview Questions	Method of Analysis
Feminist Theory	Do HIV+ African immigrant women describe experiences of gender inequality as part of their life experiences?	I am interested in learning about family gender roles and decision-making. Can you tell me a story about growing up as a female in your family? I am interested in learning about gender roles and decision-making within intimate partnerships. Can you tell me a story about growing being a girlfriend/wife/ mother?	Narrative Analysis
	Do HIV+ African immigrant women describe encounters of gender based violence, including sexual violence, as part of their life experiences?	I'm also interested in hearing the stories women who may have been hurt by an intimate partner or hurt by someone in an intimate or sexual manner. If you have had an experience like that, would you feel comfortable telling me that story?	Narrative Analysis
Critical Race Theory	Do HIV+ African immigrant women talk about contextual factors, such as poverty and migration, when they discuss their HIV status?	I am interested in learning more about women's views on how they may have contracted HIV. Can you tell me a story about a situation you feel may have contributed to you becoming HIV+?	Narrative Analysis
	What do the stories of HIV+ African immigrant women teach us about HIV?	I am interested in learning about your ideas on how to prevent the spread of HIV. When you think about your life, is there anything or anyone that you feel might have protected you from becoming HIV+?	Narrative Analysis
Theory of Gender & Power	Do HIV+ African immigrant women describe experiences of gender inequality as part of their life experiences?	I am interested in learning about gender roles and decision-making within intimate partnerships. Can you tell me a story about growing being a girlfriend/wife/mother?	Narrative Analysis
	How do HIV+ African immigrant women describe their sexual decision-making?	I am interested in learning about how people make decisions within sexual relationships. Can you tell me a story about an intimate or sexual relationship you had, what decision was made and how that decision was made?	Narrative Analysis

Feminist Theory

Feminists have long used personal narratives as a means to challenge patriarchal norms and other forms of oppression (Chase, 2005). Utilizing a feminist perspective in research provides deeper insight into the historical, cultural and social context of the participants' lives (Chase, 2005). In fact, the research itself can be viewed as a tool for empowerment. Providing marginalized individuals with an opportunity to be heard is a revolutionary idea (Chase, 2005) and can be a profound and even healing experience for many. Feminist Theory also provides guidance as to how researchers should position themselves in relation to their participants. It suggests that researchers and participants should be equal partners in the process, as the participant is the expert in their lives and the researcher has the tools to make the story heard. Thus, the researcher is nothing without the participant and serves primarily as a listener and interpreter (Chase, 2005) and less as an academic social scientist seeking specific answers to specific research questions. Finally, research questions inspired by Feminist Theory will focus on gender roles, power imbalances, and patriarchal norms, as well as reflect the importance of other forms of oppression.

Critical Race Theory

Critical Race Theory has important implications for conducting cross-cultural research as it places an individual's unique testimony above all else, while also contextualizing it in light of a hierarchical society. Critical Race Theory also points towards the use of narrative analysis to explore the words, phrases and stories used by

research participants. The theory can be used as a backdrop for understanding new and emerging forms of research interviews. For example:

> The new empathetic approaches take an ethical stance in favor of the individual or group being studied. The interviewer becomes an advocate and partner in the study, hoping to be able to use the results to advocate social policies and ameliorate the conditions of the interviewee (Fontana & Frey, 2005, p. 696).

In this research approach, it is essential for the researcher to shed their academic assumptions and take on the view of the participants in order to truly understand the world as the participant experiences it (Fontana & Frey, 2005). Thus, although the researcher and the participant live in a hierarchical society, the influence of that society should be minimized in order to build rapport and to create a "mutually accomplished story" (Fontana & Frey, 2005, p. 714). In addition to promoting equality, it is thought that this type of approach leads to the sharing of fuller, richer stories (Fontanta & Frey, 2005). Finally, research questions inspired by Critical Race Theory will elicit details regarding one's historical, cultural and social context, as well as highlight the influence of intersecting forms of oppression on one's life.

The Theory of Gender and Power

Similar to Feminist Theory and Critical Race Theory, the Theory of Gender and Power views the individual in terms of their position in a hierarchical and highly structured social context. It also recognizes that individual choices are constrained by the resulting power dynamics that lead to distinct inequalities, even within intimate

relationships. Although the Theory of Gender and Power has less to offer in terms of guidance on the relationship between the researcher and the participant than do Feminist Theory and Critical Race Theory, nonetheless, it offers significant insights into the types of concepts that should be probed by the researcher. These concepts may include: decision-making dominance, relationship control, distribution of economic and emotional resources, alternatives to the relationship, and dependence on the relationship (Pulerwitz, Gortmaker, & DeJong, 2000, p. 641). Other key concepts include sexual decision-making, power imbalances, autonomy, and differentiated gender, as well as labor roles (Wingwood & DiClemente, 2000).

Narrative Analysis

This research project is exploratory in nature, thus a qualitative approach, namely narrative analysis, was used. As previously mentioned, this study's theoretical framework pointed to the use of narrative analysis. I chose to undertake qualitative research because "qualitative methodologies often enable participants to express themselves in a more natural way, allowing for exploration of participants' experiences and meanings and providing more opportunities for their voices and perspectives to emerge" (Goodkind & Deacon, 2004, p. 730). Narrative analysis is a flexible qualitative method of inquiry (Clandinin & Connelly, 2000) used to gather information about an individual's life experiences while focusing on their social context, linking ideas and analyzing the themes that emerge from the data (Creswell, 2007). In narrative analysis, the researcher delves into the participants' first person recounting of events in their lives. These stories might include every day events, an important aspect of their lives or their whole life story

(Chase, 2005). The narratives that are shared are retrospective and seek to make meaning out of personal experience (Chase, 2005). In narrative analysis, broad questions are used as the researcher acts as a listener, respectful of the narrator's own voice and less focused on obtaining particular sought after answers (Chase, 2005). Thus, narrative interviewing involves a paradox. On the one hand, a researcher needs to be well prepared to ask effective questions that will invite the other's particular story; on the other hand, the very idea of a particular story is that it cannot be known, predicted, or prepared for in advance" (Chase, 2005, p. 662).

The role of listener continues throughout the data analysis process. Prior to analyzing themes across narratives, each narrative must first be interpreted according to the storyteller's own voice (Chase, 2005). Oftentimes, the researcher engages in "restorying" or taking pieces of the story and reordering it in a manner that highlights chronology and, thus hints of "a causal link" (Creswell, 2007, p. 56). Like any good story, narrative analysis places attention on context: time and setting which makes the stories more three-dimensional (Creswell, 2007). Narrative analysis is also useful for meaning making, thus I looked for turning points, silences and contradictions in order to glean meaning from the participants' stories (Creswell, 2007). Ambiguities and complexities are also valuable information I sought to obtain for interpretation (Chase, 2005).

It should be noted that sometimes when discussing issues as potentially traumatic and stigmatizing as gender-based violence and HIV, some women may find it too difficult or painful to share their own stories, but may feel more comfortable sharing the stories of

others. Furthermore, as previously mentioned, research participants may not identify themselves as survivors of gender-based violence and may not recognize or pinpoint the role of gender inequality in their own lives. Nonetheless, it is still important to assess the impact their experience growing up and living in communities facing these phenomena has had on them.

Data Analysis Process

Field notes were maintained throughout the data collection and analysis process. I conducted all interviews and analyzed these data, transcribed three of the interviews, and paid an assistant to transcribe the other three, and then checked the written transcript against the audio tape to ensure the transcript was of high quality and accurate. Following the interviews and their transcription, initial codes were formed. Codes were assigned in order to identify content that would later be developed into themes, as well as story elements (such as setting, characters, plot, etc.). Story elements were then used to create life histories of each of the women. Each woman's experiences were placed chronologically and key moments or influential factors in the woman's life were identified. These detailed life histories were created in order to inform the analysis process by providing a closer view of each of the women and their experiences. Due to confidentiality concerns, these more detailed life histories could not be included here. Thus, brief, less detailed life histories are included in Appendix D in order to provide a context through which the reader can gain a sense of each woman and her story without revealing potentially identifiable information. The content codes were then used to determine patterns and recurring themes, as well as interpret meanings. After the analysis

of the data collected from each of the women, themes were developed across the individual cases (Polkinghorne, 1995).

Validation Checking

I engaged in validation checking with each of the women throughout and at the end of the interview to ensure that the retelling of their stories would be in a manner that reflects how they themselves experienced the events (Creswell & Miller, 2000). For example, one participant explained that many women know that their partners are having multiple, concurrent sexual partners but do not feel able to refuse sex or to ask their partners to use a condom. Based on her earlier comments, I clarified whether this was related to the pressure women feel to marry and stay married, as their social status is closely linked to their marital status. This information was used to clarify my understanding of the dynamics involved in this relationships and the women's risk for HIV. In essence, each research participant was asked to "theorize about…her own life" (Creswell, 2007, p. 158). One strength of narrative analysis is that is respectful of the participant's telling of their own story in that the researcher recognizes the participants own interpretations and meaning making prior to beginning their own data analysis process (Pavlish, 2007).

Peer Debriefing

In order to enhance the rigor and trustworthiness of the study, in addition to engaging in validation checking with the research participants, I also engaged in informal peer debriefing with agency staff on a periodic basis to discuss general findings. Peer debriefing with agency staff, mainly case managers, and faculty mentors consisted of

trend observations and aggregate data only. Peer debriefings did not consist of information about specific, identified individuals nor individuals' responses to interview questions. For example, peer debriefing was used with the case manager in order for me to increase my understanding of the reason why some women refused to participate in the study based on fears of having their HIV status exposed. Finally, field notes were taken throughout the process and an audit trail was maintained to chronicle thinking throughout the research study (including data collection and analysis) in order to be able to track the evolution of my understanding of the topic at hand (Creswell, 2007).

Use of Narrative Analysis in Cross-cultural Research

Narrative analysis is a research method commonly employed in research with refugee populations (see Berman, 1999; Berman, et al., 2006; Parson, 2010; Pavlish, 2005; Pavlish, 2007). In fact, narrative analysis is a particularly appropriate methodology for a qualitative study in which the researcher is an outsider because allowing people to tell their own stories gives them a meaningful role in guiding the research. In fact, narrative analysis can be considered a strength-based approach (Fraser, 2004) and inherently empowering (Rappaport, 1995), as it puts value on the words of the participant herself, not the imposed direction of the researcher. Narrative analysis is a culturally appropriate methodology for research with African immigrant women. Storytelling is virtually universal. It is a natural, accessible and inviting form of communication. A reliance on oral traditions as a means of information sharing is still evident in many African communities, as well as other communities around the world.

Narrative analysis can also be empowering because it works to challenge and ultimately replace the "dominant cultural narratives" (Rappaport, 1995) that are told and retold about African women. Many of these prescribed narratives rid women of their agency, place them in a position to be pitied and only work to reinforce stereotypes. Thus, as stories have value placed on them according to the positionality of the storyteller (Rappaport, 1995), this study sought to partially rectify this situation by providing a forum through which the voices and stories of the multiply marginalized women were privileged.

CONDUCTING CROSS-CULTURAL RESEARCH

Cultural Sensitivity

As this study sought to explore the narratives of African immigrant women, it was essential to engage in respectful and effective cross-cultural research. Scholars have indicated that culturally competent research is a challenging endeavor. Hence the following discussion is important because it highlights the scholarly literature regarding how the researcher can interact in a culturally competent manner with research participants. I first discuss challenges to cross-cultural research, then review techniques I used to facilitate culturally proficient research.

As mentioned, conducting culturally competent research is difficult, given that even researchers who share the same language and ethnicity of their subjects often struggle to overcome other differences, such as social class (Tsai, et al., 2004). Unfortunately, due to the enhanced challenges related to cross-cultural qualitative research, "some ethnic groups are understudied because of the lack of linguistically and

culturally competent research staff…" (Tsai, et al., 2004, p. 17), this includes the women represented in this study. Furthermore, there is a dearth of information in the scholarly literature on this topic (Tsai, et al., 2004). Nonetheless, as the United States and the rest of the world experience an increase in migration "…it is essential to conduct research that is truly inclusive of the cultural and racial plurality present within our communities" (Goodkind & Deacon, 2004, p. 722).

Immigrant and refugee populations are a particularly vulnerable and marginalized population that is significantly underrepresented in qualitative research. This is especially true for female refugee women who are "somewhat invisible, not only in their new resettlement communities, but also within their particular refugee communities" (Goodkind & Deacon, 2004, p. 729). This can be extended to immigrants as well. Although reaching immigrant and refugee women and including them in research is not easy, researchers have found it is possible to overcome the barriers associated with this type of research through extra preparation (Goodkind & Deacon, 2004). This preparation includes building trust with research participants (Goodkind & Deacon, 2004), as well as conducting background research into the history and sociocultural context of the immigrants' and refugees' country of origin.

It is crucial that researchers create a safe environment in which participants can share information about their experience freely. This is facilitated by ensuring participants of their anonymity (Becker-Blease & Freyd, 2005), which minimizes the feelings of shame and stigma frequently associated with HIV status, as well as gender-based violence. A safe environment can also be created by setting up the room in a

manner that is cozy and comfortable, arranging chairs in a manner that facilitates direct eye contact, yet appears casual. Comfort can also be instilled through body language and tone, particularly by matching that of the participant. At the beginning of the interview, it is important to ensure that the researcher and participant introduce themselves thoroughly and that any questions the participant might have about the study have been sufficiently answered. During the interview, it is also essential to reflect the participants' word usage and respect their comfort levels in discussing difficult, even taboo subjects, such as sex and HIV. Although this level of detail into logistics surrounding intercultural research interviews may seem superfluous, it is hoped that this level of detail may assist other researchers who may want to proceed with a similar research population and line of research inquiry.

Strategies for Enhancing Cultural Sensitivity

In order to facilitate the collection of rich and culturally meaningful data, the following strategies were used as cultural considerations throughout the data collection process. First, in order to increase my sensitivity to the unique experiences of my sample population, I did a significant amount of preparation for my interviews. I reviewed the scholarly literature to gain more information on the social context and cultural practices related to the women's backgrounds, as well as their countries of origin and the factors that led to their emigration to the United States. Furthermore, I utilized my social work skills in order to ensure the participants' comfort. For example, I sought to mirror the appropriate verbal and non-verbal communication style (including tone and body posture) that worked best for each participant. Finally, the sharing of pleasantries, small talk and

food was used to assist participants in feeling more comfortable with the interview process (Goodkind & Deacon, 2004).

Language

There is a scarcity of scholarly literature on translation and the use of interpreters in social science research (Temple, 2002; Wallin & Ahlstrom, 2006; Wong & Poon, 2010). Nonetheless, this topic will continue to grow in importance due to the increasing diversity in the United States and around the world (Wallin & Ahlstrom, 2006). In fact, the need is already urgent (Esposito, 2001). Hence the following discussion highlights the challenges mentioned in the scholarly literature on effective interpretation; after which I offer considerations used to facilitate communication in this study.

The unique challenges associated with this type of research have left non-English speakers underrepresented (Lopez, Figueroa, Connor, & Maliski, 2008; Marshall & While, 1994 as cited in Wallin & Ahlstrom, 2006). Encouragingly however, a growing number of researchers are taking on cross-lingual research (Temple, 2002; Temple & Edwards, 2002), as the researcher is often not fluent in the participant's mother tongue (Goodkind & Deacon, 2004; Temple & Young, 2004). It should be noted however that the risk of misinterpreting data and meaning is enhanced when qualitative research is conducting across culture and language (Esposito, 2001).

Thus, cross-cultural research begs the question of who should represent who and how it should be done. Nonetheless, this question should be asked of all researchers, not just those speaking a different language from their participants (Temple & Young, 2004). If we assume that only researchers from the same cultural and linguistic background are

qualified to do research, then the resulting unintended consequence is that only people with backgrounds similar to the researchers' would have a voice in academic research (Temple & Young, 2004). This is problematic in that it would leave many underrepresented populations without a voice. Thus, scholarly experts recommend that the focus be placed on how the research is conducted, as opposed to who conducts it. In fact, lack of a common language can be used as a method for honest inquiry and resisting the use of assumptions (Temple & Young, 2004).

Strategies for Facilitating Communication

As the study was limited to English-speakers (who spoke English as a second language), the interviews were conducted in English. However, in order to facilitate the comfort of the participants, as well as the validity of the research, research participants had the option of requesting to have an interpreter present during the interview. None of the participants requested a translator. When the meaning of a participant's response was not clearly understood, the researcher simply probed further until clarity was reached. The researcher often repeated back her understanding of what the participants stated in order to confirm the meaning. This was done throughout the interview process.

STUDY LIMITATIONS

Generalizability and Reliability vs. Trustworthiness and Validity

This exploratory qualitative dissertation study has a number of limitations. Nonetheless, it makes a valuable contribution to the scholarly literature, especially given the lack of research on the reproductive health of immigrants. Due to the qualitative nature of the study, as well as the small sample size, this study was not designed for

generalizability or reliability. However, in narrative analysis "the meanings of these experiences are best given by the persons who experience them; thus, a preoccupation with method, validation, reliability, generalizability, and theoretical relevance of the biographical method must be set aside in favor of a concern for meaning and interpretation" (Denzin, 1989a as cited by Creswell, 2007, p. 214). Validity and trustworthiness are better criteria for evaluating the strength of this study. Richardson and St. Pierre (2005 as cited in Creswell, 2007) offer the following guidelines in terms of criteria for evaluating the strength of narrative research: substantive contribution, aesthetic merit, reflexivity and impact. Thus, it is my hope that this research will be evaluated based on these criteria.

Challenges Related to Cross-cultural Research

The evaluation of this qualitative research is complicated by the fact that cross-cultural research presents threats to both validity and trustworthiness (Tsai, et al., 2004, p. 17). Engaging in cross-cultural and cross-lingual research could leave me vulnerable to "interpreter bias" as I do not speak the participant's first language (Lopez, Figueroa, Connor, & Maliski, 2008, p. 1730). Some researchers provide specific recommendations on how to avoid this bias by following best practices in translation (Esposito, 2001; Lopez, et al., 2008). However, this study was unique in that the interviews were conducted in English with speakers of English as a second language. Thus, many of the procedures recommended for translation, for example regarding back-translation, did not apply to this study. As cross-cultural research, this study faced a number of challenges as communication is a nuanced process and culture can have a strong impact on the meaning

and understanding associated with words and language. As an outsider and a speaker of another language, this was a limitation to the study. Nonetheless, steps such as those mentioned above were taken to improve the integrity of the research.

Limits Related to the Use of Cultural Informants and Validation Checking

Research on cross-lingual studies suggests including members of the participants' community in the research process, including the analysis of data (Tsai, et al., 2004). Unfortunately, due to the stigma associated with HIV and the need to maintain strict confidentiality, this was not possible. It is hoped that informal debriefing with agency case managers compensated for this missing input.

It is often considered a best practice to check your interpretations with participants after the interview process (Fraser, 2004), however, due to the stigma associated with HIV and the importance of confidentiality, I decided to forego this step in an effort to maintain the participants' confidentiality. A short check-in with each participant at the end of her interview replaced having an additional meeting or providing her with a written analysis.

Limitations of Participant Inclusion Criteria

Another limitation was that due to the small size of this exploratory qualitative study and limited research funds, the study had to be limited to English-speakers. This was a significant limitation, as it can be reasonably assumed that those HIV+ immigrants who do not speak conversational English may have different lived experiences and service needs. Therefore, although this study sought to give voice to a hard-to-reach population of marginalized and highly vulnerable women, it fell short of providing an

equal opportunity to all HIV+ immigrant women. Furthermore, the study participants were from multiple African nations. The study participation was opened in this manner due to the difficulty in obtaining a sample of English-speaking HIV+ women. In order to mitigate the added complexity of having women from multiple nations and cultural traditions, each woman and her experiences were addressed with humility and curiosity in order to understand her particular situation, as well as the meaning she subscribed to it.

RESEARCH SUBJECTIVITY

Research subjectivity is an inherent part of qualitative research. It influences the selection of the topic, how the researcher formulates the hypotheses and research questions, and the approach to data analysis and interpretation (Ratner, 2002). A key issue that arises in the discussions on researcher subjectivity is the ability to remain aware of one's biases. For this reason, qualitative researchers are encouraged to reflect on how their values, socioeconomic background, and other important factors affect the research process (Ratner, 2002). For these purposes, this section discusses my observations with respect to recruitment and the interview process, and my reflections on how my race, ethnicity and socioeconomic background influenced the dynamics of interviewing HIV + African immigrant women.

Recruitment and Interview Process

As this is an exploratory study, I have included this section to record the process that was undertaken in order to share lessons learned for other researchers planning to conduct similar studies with HIV + immigrant women.

Participant Recruitment

Recruiting women for this study presented some formidable challenges. The main challenges were related to the women's fear of having their HIV status exposed. Due to confidentiality issues, the case manager was the center piece of the recruitment process. As I was not able to contact the women directly, I met with the case manager to explain the study and then she contacted the women by phone to invite them to participate in the study.

Going into the process, the case manager stated that of all the immigrant women they serve, the African immigrant women are the most concerned with confidentiality due to the stigma in their community and, therefore, would be much less likely to participation in the study. Despite this recognition, she stated she was still surprised by how difficult it was to find women willing to participate in the study. Some women would not return her phone call because they knew it was about a research study. The women she did speak to expressed concern about confidentiality and that concern discouraged them from participating. In one interaction, after explaining the study to one woman, she mentioned the incentive and the woman responded negatively stating that she didn't want to "sell" her story. In another example, one woman agreed to participate in the study. However, before an interview could be scheduled, an older male relative made her contact the case manager and decline participation because he didn't want her to share her story.

When women had questions regarding my interests in conducting the study, the case manager explained my study aims. Most likely, it would have been helpful if women

who had participated in the interview process could have spoken with potential participants to give them information on their experience being interviewed. I believe this would have given additional women the comfort they needed to participate. However, because the majority of these women are not openly receiving services, they were not in communication with each other. Therefore, there was no one besides the case manager to vouch for me that I had good intentions or that it was a positive experience. Working with a community of women who were in communication, such as support group participants, would allow the researcher to benefit from word of mouth support for their project.

Other recruitment difficulties were related to the narrow eligibility requirements. This made flyers, presentations to support groups and other typical recruitment activities unhelpful. If the women had been coming in regularly for weekly services, it would have been possible for the case manager to invite them in person. That may have also allowed me to attend the preliminary meeting to explain my interest and intentions.

Interview Challenges

One of the largest challenges in conducting the interviews was timing. I had hoped to speak with each of the women for at least two hours. However, it turned out that most of the interviews lasted about an hour and a half. By that time, they either had transportation they needed to catch and/or children who were getting antsy, etc. I wish I had more time with each of the women, but logistics did not seem to allow it. Transportation issues made some participants late and forced others to leave early. Two of the women brought their small children with them to the interview. Only one of the

children was old enough to understand the content of the interview, but we were able to provide entertainment for the child, so she wasn't able to hear our conversation.

As it was expected that the participants would speak English as a second language, I had anticipated that we would run into difficulties with language and was pleasantly surprised that it did not feel like a formidable challenge in this study. The women had varying levels of English speaking capability, as well as literacy. Some grew up speaking English from the time they first entered grade school. One woman had limited literacy in her own language, as well as in English, and had been practicing signing an X for her name. The day of the interview she expressed her concern to the case manager that she didn't feel skilled in reading or writing English and she was worried that it might come up during the interview. The case manager reassured her and the issue never came up in the interview since there weren't any reading or writing components to the interview. But all of the women spoke using very rich, descriptive and meaningful language. I soon became familiar with the few local colloquialisms that arose and there were times when I had to probe further following their responses, but at no point in any of the interviews did we come to a standstill due to language.

Issues of Confidentiality

In order to maintain the strict confidentiality of each woman, the case manager was the one to contact them and schedule the interview. The study was set up so that I did not have the real name of the participants. At the beginning of each session, I simply asked the women by which name they would like to be called for the purpose of our interview and the study. Nonetheless, there were a couple of times in which the case

manager or the woman herself introduced herself with her real name. In these cases, I did not record the name, nor did I use it in our interview. In order to protect their anonymity, I also obtained a Waiver of Documentation of Consent so the women did not have to sign anything. After the interview several of the women mentioned that they were open to staying in touch with me. I responded by stating that I would like to stay in touch, however, my main priority is to protect their identity and, therefore, I did not maintain any contact information for them.

For some of the women, their fear of exposure was palpable. For example, during the interview with one of the women, there were a number of times where there was some noise, such as walking or talking, coming from outside of the room in the hall. Whenever a noise would come up outside, she would look nervously toward the door. I interpreted that to mean that she was concerned that someone might enter the room or hear her voice and story. Even though we were in a room by ourselves with the door shut, it seemed as though she was still scared that she could somehow be identified.

Due to the study's strict confidentiality and the women's fear of having their HIV status exposed, I felt very honored to have access to these stories. I wrote about it in my field notes stating:

> And I have this feeling of being a "keeper of secrets". These are women who haven't shared with other people that they are positive. So in a way I feel like a "keeper of secrets". In another way, I feel like an announcer; I am telling the world these stories and that feels very humbling.

Participant Demeanor During Interview

The women's demeanor and behavior during the interview varied from woman to woman. Some women were quieter and more hesitant. Others were more outgoing and very open about sharing their experiences. For example, Kiza spoke about her experiences in the third person in a way that was sometimes difficult to tell if it was her personal experience or the general experience of others in her community. On the other hand, Brenda Lynn was very open and quickly launched into sharing experiences about sexual violence. Even though she seemed eager to talk about her experiences, based on her voice and affect, it was clearly painful for her to discuss. Liz was also open, yet vulnerable, and it was clear that her experiences still had a lot of meaning for her. Half of the women cried during the interview while telling their stories. There was also a lot of humor and laughter during the interviews; there was a lot more humor than there was sadness. In selecting quotes to be included in the analysis, I sought to pick passages that captured the women's lively spirits and feistiness. It is my hope that their voices come alive through the narrative.

Participant Reactions Following the Interview

In general, the women's responses to the interview process were very positive and I didn't receive any negative feedback. Kiza, who was a bit more reserved than the other participants, told the case manager that it was a bit uncomfortable talking about these issues, but overall it was a good experience. After Brenda Lynn's interview, we hugged and in the hall and she hugged me again. She thanked me enthusiastically and made a point of referring to herself by her real name. I interpreted it to be a sign of trust and

closeness that she wanted to share her name with me. Brenda Lynn also called the case manager a few times to express her gratitude and excitement, stating that she was really grateful for the opportunity and said that no one had ever asked her those questions before and she was glad to talk about it. She said she never had a chance to talk from her heart so much and that she enjoyed it. Liz also called the case manager and said she was happy to participate and was really glad to share what she did. I felt elated to know that these women really embraced and enjoyed the experience. Due to the difficult topics we discussed, such as sexual violence, I was hoping the interview would feel at least neutral and do no harm to the participants. So, it was great to know they had positive experiences.

Personal Reflections

Identifying with Research Participants

Throughout the interview process I was constantly struck by how strongly I identified with these women. I felt so connected to them because they reminded me of the women I met in Kenya in terms of shared risk factors and vulnerabilities, and how so many aspects of their reproductive health were out of their control. And yet even in that context they have done everything they can to exercise their agency to improve their lives and control their own decision-making. Not only did they remind me of the women I met in Kenya, but most of all, they reminded me of myself. What was difficult about identifying so closely with the women was that they were most likely largely unaware of this likeness. Although the details of our experiences are different and mine took place in an American context, there are so many commonalities in terms of being a woman in a

sexist and patriarchal society in which the culture doesn't always allow for you to be in control of your own body and decision-making. I explained it as follows in my field notes:

> I think one thing about this process that seems so odd to me is that I identify so strongly with these women and I imagine that they may have no idea. I mean I think we are doing a good job developing rapport because they are sharing stories with me. But I don't think they have any idea how much solidarity, connection and empathy I feel for them. Basically connection, obviously in very different contexts and social environments, but dealing with the same issues: just being a woman and trying to negotiate your sexual and reproductive health within the confines of a sexist society and how challenging that can be.

I continued to feel connected to these women throughout the interview process and recorded these feelings in my field notes, as well:

> Driving here today I was crying just thinking about these women. I keep having this sensation that I am falling in love with these women. Not in a romantic sense, but just all their vulnerability and simultaneous strength. How can you not love these women? How can you not identify with these women?

In retrospect, I believe some of the connection I felt to the women was enhanced by the fact that I was pregnant with my first child at the time of the interviews. With the exception of one woman, all of the women had children. My pregnancy seemed to create

a closeness with the participants in terms of sharing a universal, yet deeply personal and emotional experience. My pregnancy and the upcoming birth of my son provided us with an opportunity for small talk and seemed to highlight the commonalities of our human experience, despite the different contexts in which we grew up.

In addition to struggling with the fact that they did not know how I identified with them, I wanted to do more to thank them as I was so honored that they shared their stories with me. I also wished that the study was more of an intervention so that there was something I could offer them in exchange for their truth and courage. In preparing for these interviews, I had prepared to share a bit about my interest and even some of my own experiences, just briefly, in order to make the experience more mutual. But in general the women didn't ask me and I in no way wanted to make the interview about myself. There were a few times where we shared a knowing laugh or I told them I had been in a similar situation and I think those moments gave them a hint of the solidarity I felt and built a bridge between our experiences. But in large, I didn't know how to convey that other than to share food and drink with them during the interview and thank and hug them at the end and tell them I appreciate their sharing with me and that they are strong women. But it seemed like such a small thing in return. I wish I had time to talk with them just woman to woman or have multiple interviews so I could share more of my experience with them so they knew how much I identify with them in order to universalize their experiences. I'm just so grateful to them and I hope they sensed it in my interaction with them. I continue to feel a lot of humility and gratitude for what they shared with me.

Issues Relating to Difference

I was acutely aware of my race throughout the recruitment and interview process. The first time the issue of race came up was while the case manager was trying to recruit women to participate in the study. Apparently, more than one woman asked her if I was African, African American or White. Their preferences can only be assumed, as they didn't state it explicitly. What I do know is that they were concerned about my race and country of origin. They also wanted to know my interest in this topic and they asked the case manager to explain my interest to them. What is interesting is that only one of the women asked me a pointed question about my interest in studying HIV+ African immigrant women and how the results would be made public. Interestingly, that woman had a post-graduate education. She said she was very eager to participate in the study because there are a lot she wanted to let people know about HIV and African women.

I would like to think that the participants didn't question me directly about my interest because they found me warm and friendly and this may have disarmed them of concerns that they previously held. I cannot know for sure, however, some of the other participants may not have felt comfortable addressing this issue with me due to my privileged position. I was keenly aware of my privileged position as a white, middle class, American-born, English-speaking woman interviewing Black, African-born immigrant women of varying class statuses (but most commonly working class) who are speakers of English as a second language. I was also aware of my position as a student scholar trained in a Research I university who was asking very personal information about their private lives. Furthermore, while I had the luxury of designing and pre-

rehearsing research questions, the participants were being asked to respond to the questions without having had the advantage of pondering them prior to the interview.

In recognizing it might be difficult for the participants to question me and my intent, I tried to openly offer my interest in the study, although admittedly, my interest statement was overly academic. I worked to develop rapport with the women and make a connection, even during such a short timeframe, in the hope of not being perceived as a random white woman interviewing them about very personal aspects of their lives. I believe they saw my sincere empathy and my lack of judgment, but I worried that they may feel as though their stories were some kind of academic curiosity of mine and it is much more than that for me. But regardless of the effort I put into building rapport with each of the women, at the end of the day they may have still seen me as a white academic with an academic interest. They may have been largely unaware of my personal interest and the passion I have for these issues.

There were a couple of times during the study in which I felt my race had an impact on the interview or the analysis process. For example, two of the women had partners from the United States who were American-born citizens and I wanted to know the race of their partners. However, I chose not to ask that question. I felt as a white person, the question might seem like a mere curiosity, or an invasion of privacy as opposed to informative data. I don't know whether I should have asked the question because it may have been relevant and added to my understanding of their experiences. Nonetheless, in terms of being reflexive, had I shared their race, I may have felt more comfortable probing into the race of their partners. However, at the time, I felt it was

much more important and relevant to their narratives that they were African immigrant women living in the United States with American-born partners.

Another example where I was aware of my race during the interview process is when the women would make comments about "African men". I felt awkward in those moments because I wanted to be affirming in my body language (as I tried to be throughout the interview process), however, as a white woman, I felt it was important not to buy into stereotypes about African men. Although the women's experiences with men were valid and social norms vary from culture to culture, I know that African men are not the only men engaging in behavior, such as having multiple partners. I imagined that if I was having this conversation with American-born women, they would probably make similar comments about American men.

In terms of culture, there was an interaction while discussing sexual violence in which although the participant acknowledged the existence and even the prevalence of sexual assault, she was adamant that people from her community do not recognize the concept of marital rape and would not use terms such as "rape" to define their experiences. There seemed to be a moment in which she felt as a white American woman I may not be able to understand this; perhaps not realizing that it wasn't very long ago in the United States when we began to officially recognize marital rape and that there are still plenty of people in the United States today who do not recognize it.

Finally, another example during which I became aware of my difference related to silence and disclosure. In the United States and in western culture in general, we have a focus on "talk therapy" and talking out our problems. Thus, it was difficult to put my own

perspective aside when looking at issues such as disclosure. These women had made careful decisions regarding disclosure that they judged were best for them. I kept thinking about how important it is to "break the silence" about intimate partner and sexual violence, as well as HIV. I also found myself believing that it is essential to reach out to at least one trusted individual to disclose one's status in order to prevent social isolation and promote help-seeking behavior. Even though I tried to simply listen, probe and understand during the interviews, sometimes my own American values on power, control, decision-making and gender equality may have come through too strongly in the analysis.

Chapter Four: Findings

PREFACE

This research study analyzed the narratives of HIV+ African immigrant women in order to learn about the role of gender-based violence and inequality on their reproductive health and disease status. The analysis of the data that was collected from interviews with six HIV+ African immigrant women follows. The six women who participated in the study are named: Brenda Lynn, Kiza, Liz, Marica, Mary, Michelle (names changed to maintain confidentiality). I begin this section by providing a general description of the women who participated in the study. I then describe the overarching themes that emerged from the narratives the women provided in response to the research questions. The overarching themes include: marriage as a vulnerable status; gender inequality and gender-based violence as norms, and; the cycle of stigma and silence. Thereafter, I review each of the research questions and present the sub-themes that emerged for each question.

It is important to note several topics before presenting the general description of the participants, overarching themes, and the sub-themes for each research question. First, the reader is reminded that a life history for each of the six study participants is included in Appendix D. In addition, several notes regarding confidentiality, diversity of narratives, and culture are included below.

Preface Regarding Confidentiality

Due to the need to maintain the strict confidentiality of the women who participated in this study, many of the personal details included in their narratives could not be included in this analysis. Furthermore, details regarding their case managers or

program services also could not be included, as they may identify the AIDS organization and potentially expose the women as clients. Therefore, I have sought to omit all identifying information. Nonetheless, I have included the richest detail possible without including descriptions that were specific to the individuals; thus making them identifiable. For example, in cases where details of a story could be identifiable (such as having a particular illness) but were relevant to the analysis, I included the information without associating it to a specific participant. I have taken these precautions because the safety and confidentiality of the women who participated in this study is my top priority. The possible consequences of revealing identifiable information on the participants, includes unsanctioned exposure of HIV status, thus, potentially exposing the women to stigma, social isolation and even violence. Thankfully, these women were willing to share their stories despite stigma against HIV+ individuals. A couple of them explicitly said they wanted people to know about the spread of HIV in their community.

Preface Regarding Diversity of Narratives

It is my intention that this research add to our knowledge and understanding of the unique experiences of HIV+ African immigrant women, and shed light on the dynamics fundamental to the transmission of HIV in the broader community as well. One of my goals in conducting this research study was to expand the narratives that are told of African women and, thus, African immigrant women. I am very conscious that my research not reinforce stereotypes or misconceived notions about this population. In no way do I mean to depict African immigrant women as powerless victims, nor the men in their lives as domineering. This research study, by nature, exposed a variety of negative

situations and behaviors as it explored the role of gender-based violence and inequality in the spread of HIV. Thus, sanitizing the findings would not serve a constructive purpose. However, it is important to state that such a study, regardless of the research population, would uncover unsavory findings as it specifically looked for examples of gender-based violence and inequality so they can be effectively addressed in an effort to prevent the spread of HIV. The examples included in these narratives of ways in which the women have been made vulnerable to the spread of HIV are due, in large part, to the patriarchal socialization that takes place in almost every society. Though the expression of this patriarchy manifests itself differently in each context, the underlying principles are the same. Therefore, though somewhat different, comparable examples would most likely also be found in a sample of American-born United States citizens. A sample of HIV+ African immigrant women was specifically selected due to the high HIV infection rates in sub-Saharan Africa, as well as to explore the unique contextual factors affecting immigrant women. When reading these examples, I ask the reader to be aware of similar examples in their own country of origin.

As previously mentioned, I have removed specifics of the women's stories that might be identifying. This includes description of the many characters that feature in their narratives, including family, friends and loved ones. Therefore, I would like to state that in just six interviews, I witnessed a great diversity in terms of the participants and the women and men in their lives. The women, their female friends and relatives included: medical professionals, business owners, farmers, academics, women who married young, women who married late, women who bucked tradition, care givers, and heads of

households, etc. The men, including American-born citizens, in these women's lives were comprised of: business owners, laborers, addicts, political figures, perpetrators, confidantes, caring husbands, protective sons and great fathers.

Preface Regarding Culture and Religion

Culture is about expected norms and behaviors that are often passed down from one generation to the next. Culture certainly plays a large role in carving out gender roles and expectations. Nonetheless, culture is a broad and ubiquitous phenomenon that is hard to define and is not the focus of this study. As a white American-born woman interviewing Black African-born women from five different nations, it wasn't feasible to be an expert in each of their cultures, especially when cultural beliefs and practices often vary community by community. Furthermore, culture is not the only factor influencing behavior. According to the World Health Organization "…individual choices and behaviors are embedded in many layers of social and community context, from marriages and extended families, to communities and countries" (WHO, 2010, p. 1). In addition to culture, sexual behavior is also influenced by politics, socialization and the economy (González-López, 2005). This makes it difficult to understand the distinct role culture plays in affecting one's sexual health.

Culture is not uniform, nor is gender inequality and rates of gender-based violence. González-López (2005) developed the phrase *"regional patriarchies"* to highlight that the nature and impact of patriarchy, and thus gender inequality, is not uniform across a culture or even a nation, but is instead determined at the local level. This large variance in contextual factors also creates a large variance in HIV infection rates

across different communities, hence the impact of HIV/AIDS is not homogeneous throughout a nation (UNAIDS, 2005). Consequently, in order to mitigate the added complexity of having women from multiple nations and cultural traditions, each woman and her experiences was addressed with humility and curiosity in order to understand her particular situation. Therefore, in this study I purposefully approached culture as the women reported it to me in terms of gender norms and expectations that influenced their lives. Although I wasn't able to directly observe these norms and expectations in action, I was able to learn about them from the women's own vantage point. For me, this was preferable since each woman is the expert on her own culture. When beliefs or practices were not clear, I continued to probe to enhance my understanding.

It should also be noted that religion plays an important role in defining and shaping culture. This influence again shows the complexity of understanding culture as each nation and even community is made up of individuals practicing a variety of faiths. Religion also has significant influence over gender roles and expectations and what is culturally sanctioned. Interestingly, research has shown that spirituality can be used as an important coping strategy for dealing with and making meaning out of being HIV+ (Hampton, 2005; Hodge & Rohy, 2010; Polzer Casarez & Shandor Miles, 2008).These different sides of the issue led the women to report different experiences attending church services; positive experiences gaining social support, as well as negative experiences in terms of it being a site where narrow gender roles were sometimes promoted and reinforced by attendees. As the women in this study all identified as Christian, issues related to religion surfaced in their narratives. However, because the focus of this paper is

on the role of gender inequality and gender-based violence on risk for HIV, religious issues were only reported as they related to those topics.

DESCRIPTION OF THE PARTICIPANTS

Below, I have included general information about the women who participated in the study, as well as their experience learning of their HIV status. I have done so in order to provide a sense of who they were without revealing details that may lead to the identification of participants. In order to strike a balance between introducing the reader to the context of each of the participant's lives and maintaining their strict confidentiality, I have also included a brief life history for each of the women. Please see Appendix D. More detailed life histories were created in order to inform the analysis process by providing a closer view of each of the women and their experiences as HIV+ women. They are not included here in order to preserve the women's confidentiality.

The sample of research participants was obtained from the clients of an AIDS service agency in the southwestern United States. The six African immigrant women I interviewed for this research project hailed from five African nations. These nations included: Burundi, Cameroon, the Democratic Republic of the Congo, Malawi, and Zambia. Their ages ranged from their 20's to their 60's. Although the women each grew up speaking a local or regional language, four learned some English in their country of origin. They have been living in the United States from three to 35 years. One of the women was a United States citizen, two are permanent residents, two are undocumented and one is seeking asylum. These women represent great diversity in terms of their education and employment history. Their educations ranged from elementary education

all the way through graduate school. Their work included subsistence farming, manual labor, customer service, international trade and medical care. In their countries of origin, the women ranged from living in poverty to living a relatively wealthy lifestyle. Once they completed the migration process and resettled in the United States, they would most likely be considered working class, though one or two of the women could be considered middle class. Although participation in the study was not limited to heterosexual women, all of the women reported being in or having been in heterosexual relationships. None of the women disclosed having or having had a same-sex partner. The women were married, divorced (or estranged from their husbands/live-in partner) or widowed. One woman had no children. The other women had from one to nine children. The ages of their children ranged from one to the mid 40's. Some women had their children with them in the United States. Others had some or none of their children with them. Besides their children, the majority of the women did not have close family members with them in the United States. All women identified as Christians and participate in religious services at least occasionally, though most participate regularly.

Five of the women were tested for HIV in the United States; of these women four were tested while receiving medical care for another health issue. One woman was tested in her home country. They have also experienced a number of physical health (including tuberculosis and cancer) and mental health (including depression, anxiety and suicidal ideation) issues. They have known their HIV status from two to 20 years and have been receiving services at the AIDS organization for less than one year to more than 15 years. One woman had an adult child in her home country who died from AIDS. Another had a

child that is infected and living in the United States. Although it is difficult to pinpoint the exact mode of infection, four of the women believed they were infected by their husband/live-in partner although one of the women stated she may have contracted HIV during a period in which she engaged in survival sex. One of the women believed she was infected through a blood transfusion and the final woman did not know how she was infected.

BACKGROUND INFORMATION ON COUNTRIES OF ORIGIN

In order to understand the context from which the women who participated in this study came, it is important to have background information about their countries of origin. The nations represented in this study fell victim to exploitation from European colonial powers. In general, once the nations gained their independence, many of them experienced a period of unrest and even civil war, while various ethnic groups and constituencies volleyed for power in the wake of devastation left by the colonial powers. Thus, the legacy of colonialism and its ensuing period of unrest, often left these countries vulnerable to poverty and violence, both of which place women at risk for contracting HIV. The countries from which these participants were born are complex, diverse nations. The summaries presented here are brief to give the reader an initial context and therefore are not comprehensive.

Burundi

Burundi was colonized in 1887 by Germany which ceded control of it over to Belgium after its defeat in World War I. At that time, Burundi was combined with Rwanda and named Ruanda-Urundi. The Belgian colonizers used Tutsis to administer the

colony. Burundi gained its independence from Belgium and separated from Rwanda in 1962. Although not as well known as the genocide in Rwanda, Burundi also experienced genocide resulting from the regional conflict between the minority Tutsis and majority Hutus. This conflict was the result of escalating ethnic tensions fostered by colonial rule. The country was embroiled in a civil war in 1993 (History World, n.d.). As in most conflicts of this magnitude, rape was used as a weapon of war and perpetrators were often not held accountable (Amnesty International, n.d.). Due in large part to the devastations of war, Burundi remains one of the world's poorest countries. According to the United Nations (2008), violence against women is a public health threat there and women are vulnerable to HIV due to economic dependence, sexual violence and widows and orphans engaging in prostitution for survival (United Nations, 2008). The official languages in Burundi are Kirundi and French.

Cameroon

Cameroon is located in west Central Africa. A former German colony since 1884, Cameroon was divided between France and Britain after World War I. Thus, its official languages are French and English. In 1960, it gained independence from France and was united with the British occupied land the next year. A civil war took place due to conflict between the majority French-speakers and the minority English-speakers (History World, n.d.). The country enjoys political stability (United States State Department, 2013). Nonetheless, the United Nations (2000) has identified a number of local practices and customs that negatively affect the status of women. They include: forced marriage, sexual

violence, female genital mutilation, violence against women, early marriage, barriers to inheritance and poor treatment of widows.

The Democratic Republic of the Congo

The Democratic Republic of the Congo, a French-speaking nation, was under the rule of King Leopold II of Belgium beginning in 1885. Ironically named the Congo Free State, the Belgium government later took it over after King Leopold's brutal regime during which millions of Congolese died or were killed. The nation gained independence from Belgium in 1961. The United States and Belgium later helped install President Mobutu who quickly became a dictator. After he was ousted in 1997, civil war ensued due to ethnic tensions and desire to control the Congo's vast mineral riches, including copper and diamonds (History World, n.d.). The Congo has been embroiled in civil war since 1998 and conflict still continues in some areas today. Unfortunately, millions of people have died or been displaced as a result of the civil war (Amnesty International, n.d.). Moreover, the conflict is often described as the most severe purposeful use of rape in the world due to the frequency and intense violence associated with the acts (McCrummen, 2007). According to the United Nations (2006), the civil war largely destroyed the economy and led many to live in poverty. Rampant sexual violence, lack of accountability for perpetrators, illiteracy, lack of women in leadership positions and discrimination in legal matters continue for women are also major concerns (United Nations, 2006). Finally, the Democratic Republic of the Congo is considered one of the worst places to be a mother due to violence, poverty, lack of information and maternal mortality rates (Amnesty International, n.d.).

Malawi

Scottish missionaries settled in Malawi as early as 1876. The country, located in south east Africa was officially colonized by the British in 1891. It gained its independence in 1964 (History World, n.d.). It is a largely agrarian country with very high HIV rates. Interestingly, Malawi has a female President, Joyce Banda. The country is currently experiencing growth due to agricultural success and foreign investment (Amnesty International, n.d.), yet still remains one of the world's poorest countries (United Nations, 2004). Some of the factors negatively affecting women there include: sexual exploitation, lack of women in leadership and decision-making positions, gender inequality in education, violence against women and strictly socialized gender roles (United Nations, 2004). The official languages are Chichewa and English.

Zambia

Zambia is a former British colony and an English-speaking country. After decades of administration by the British South Africa Company in order to exploit the nation's vast mineral wealth of gold, diamonds, zinc and copper, British rule officially began in 1924, although the company maintained mineral rights to the land. The country also gained its independence in 1964 (History World, n.d.). While largely impoverished, its wealth has risen and declined based on the market for its rich mineral resources (United Nations, 2002). Zambia has a stable democracy (Amnesty International, n.d.). Nonetheless, key issues continue to negatively impact women living in Zambia. They include: discrimination in legal matters such as inheritance, gender stereotyping, prostitution and lack of women in leadership (United Nations, 2002).

State of the Nations

Based on data collected by international bodies, such as the United Nations, it is evident that the situation for individuals living in these countries is not easy. The countries experience low life expectancies and widespread poverty. Based on a human development index created by the United Nations Development Program (UNDP) that takes life expectancy, education and income into account in order to provide a universal comparative measure for development, out of 186 countries, these nations rank among the least developed (UNDP, 2011). See the figure below for more detailed information.

Figure 7: International Human Development Indicators (adapted from UNDP, 2011).

	Human Development Index Rank	Life Expectancy	Mean Years of Schooling (of Adults)	Average Annual Income
Burundi	178	50.9	2.7	$544
Cameroon	150	52.1	5.9	$2114
DRC	186	48.7	3.5	$319
Malawi	170	54.8	4.2	$774
Zambia	n.a.	49.4	6.7	$1358

Violence Against Women

In 2011, data from various international studies were compiled by United Nations Women (UN Women). A 2004 Demographic and Health Survey found that in Cameroon, 39% of the sampled women had ever experienced physical violence and 14% had ever experienced sexual violence within an intimate partnership (UN Women, 2011). In comparison, 2007 data for the Democratic Republic of the Congo revealed that an astounding 57% of the sampled women had ever experienced physical violence and 35% had ever experienced sexual violence (UN Women, 2011). Data collected from Malawi in

2004 showed 22% and 13% respectively, while 2007 data from Zambia revealed 47% and 17% respectively (UN Women, 2011). Burundi was not included. An international study conducted by the United States Agency for International Development (USAID) of ten developing counties, including Malawi and Zambia, found that 13% of Malawi women had experienced physical violence by an intimate partner within the last year and 12% had experienced sexual violence during the same period (2008). For Zambia, the rates were higher at 25% for physical violence in the last year and lower at 5% for sexual violence in the last year (USAID, 2008). Unfortunately, information collected by USAID reveals that the laws and policies of these countries do not protect women in a comprehensive manner. The data reveal that although each of the countries have laws protecting women (except Zambia), as well as policies geared towards reducing violence against women, the countries also have laws working against those provisions that actually serve as obstacles to protecting women (USAIDS, n.d.).

Women and HIV

According to 2009 data from Avert, an international AIDS organization, HIV infection rates for the nations represented in this study are as follows: Burundi 3.3%; Cameroon 5.3%; the Democratic Republic of the Congo 1.2-1.6%; Malawi 11%; and Zambia 13.5% (Avert, n.d.). As discussed earlier, violence and discrimination against women puts them at risk for contracting HIV. Figure 8 below provides information on key indicators of women's health, including HIV status.

Figure 8: Women's Health Indicators (adapted from Population Reference Bureau, 2011).

	% of women age 20-24 married by 18	Lifetime births per woman	% married women using modern contraception	Maternal deaths per 100,000 live births	% female adults ages 15-49 with HIV/AIDS	% male adults ages 15-49 with HIV/AIDS
Burundi	18	5.4	8	970	4	2.6
Cameroon	36	4.7	13	600	6.4	4.3
DRC	39	6.4	6	670	n.a.	n.a.
Malawi	50	6.0	38	510	13.2	8.9
Zambia	42	6.2	33	470	16.0	11.1

OVERARCHING THEMES FROM CURRENT STUDY

The overarching themes cover information gathered in response to multiple research questions and were selected due to their frequency, salience, and meaning in the women's lives. The principle finding for the study is that the women experienced marriage as a vulnerable status that put them at risk for contracting HIV. There is significant pressure on women to marry and stay married. Once they are married, the decision-making process they observed in their families of origin and in the larger community affected their sexual decision-making in their intimate relationships (making it difficult for them to say "No" to sex or ask their partners to use condoms). Their narratives shed light on the role of gender inequality and gender-based violence in the lives of HIV+ African immigrant women. Gender roles and expectations create inequality in their lives, as well as establish accepted norms of behavior that continue to influence them in their intimate partnerships. Thus, we witnessed their experiences of sexual, physical and emotional abuse, as well as physical and emotional neglect. We also learned

that their fears regarding having their HIV status exposed related to the overwhelming stigma faced by HIV+ individuals within their community. This stigma led many of the women to keep their status secret, even from family and loved ones.

Marriage as a Vulnerable Status

The overarching theme in the women's narratives was that marriage is a vulnerable status that can put women at risk for contracting HIV. This vulnerability is based on social norms that state women should marry and stay married. Once women are married, they: 1) should *not* say "No" to sex with their husbands, 2) should *not* ask their husbands to use a condom, and 3) should *not* divorce husbands/leave partners for having concurrent sexual partners. Thus, married women and women in long-term committed relationships that are recognized by their community often find themselves in situations in which they know their partner has multiple concurrent sexual partners, however, social norms prevent them from being able to refuse to have sex with their husbands or to demand that their husbands use condoms. These factors put women at risk for HIV and are further complicated by family structures allowing multiple wives. Some of the social pressure to remain in these situations is due to a belief that a woman's status is raised when she is married and that divorce will smear her reputation or that of her entire family. Thus, oftentimes, married women will endure conflict and even violence in order not to lose that important social status. In some communities, such as those in which marriage is often not formalized, it is easier to leave a partner, however, the belief that infidelity is not a reason to end a relationship continues to influence women in that context. Another factor putting married women at risk is that often when women say

"No" to having sex with their partner or ask their partner to use a condom, their partner accuses the women of cheating on them. This may lead to discord in their relationship and may also sully the woman's image in the community.

One narrative that highlighted this theme of marriage as a vulnerable state was Mary's experience contracting HIV from her husband in her home country, a land ravished by war. She survived a horrendous war, in which her husband was arrested and killed. She was subsequently arrested as well but was able to escape with the help of a male family member. As with other wars, the conflict she survived was rife with sexual violence which was used against the population as a tool of war. Despite having survived the war and avoided incidents of mass rape, she contracted HIV from her husband. For Mary, being married was a bigger risk factor for contracting HIV than living in a war torn country punctuated by rape. Her lived experience as a married woman to a man with concurrent sexual partners was her largest risk factor.

Women who are financially vulnerable are also at risk for contracting HIV. In this case, marriage is often viewed as a protective factor. However, these narratives show that being married does not always make a woman more financially stable. Moreover, having children can add financial pressure which can increase women's vulnerability and dependence. Sometimes male partners may refuse to share their income for the benefit of the woman and their children. Brenda Lynn provided a telling example of how these factors interplay to put married women at risk for contracting HIV. Brenda Lynn, who engaged in survival sex to support her family after leaving her husband, explained that many married women in her community secretly engage in survival sex in order to

provide for the financial needs of their families. Unmarried women with children out of wedlock also engage in this behavior, but it is interesting to note that in cases similar to Brenda Lynn's, marriage is not a protective factor. Survival sex also reveals how contextual factors, such as poverty, put women at further risk for HIV.

Gender Inequality and Gender-based Violence as Social Norms

The narratives the women in this study shared clearly showed that gender inequality and gender-based violence are social norms. Much of the gender inequality that was mentioned was in relation to family decision-making power. Half the women who participated in the study grew up in homes in which the men made decisions, in terms of finances, education, etc. In some situations, the husbands and wives would jointly discuss issues, however, when disagreements arose, it was the men who had the authority to make final decisions. The larger social structure, including the greater influence of the husband's family on a new couple, also supported the dominance of men. In contrast, Michelle grew up in a family in which her mother and step-father made independent decisions regarding their finances and business enterprises. Mary grew up in a household dominated by her step-mother due to her father's fear of confronting her and getting divorced for a second time. Michelle stated that her father used to be the main decision-maker in the family, but that changed after her family moved to the United States so both her parents could pursue their graduate degrees. After returning to their home country, Michelle stated that her mom tended to be the more dominant of the two in terms of decision-making. It is unclear whether these changes were due to exposure to mainstream United States society. It does not appear that these differences are due solely

to education level as a number of the family members of other women in the study also had advanced academic and professional experience. Interestingly though, the women who grew up with equal or even dominant mother figures all stated that they were keenly aware that the decision-making process in their home was unique and did not follow the norms for their community.

The norms the women experienced in their families of origin and in their larger communities greatly impacted decision-making in their intimate partnerships. The same is true about other aspects of their relationships as well, such as men having multiple concurrent partners. Happily, Marcia and Michelle followed the strong examples of their mothers and married men with whom they had very open and respectful decision-making processes. For example, they were able to actively engage in sexual decision-making with their husbands; jointly making decisions about issues such as using condoms, getting tested for HIV and having children. Michelle even laughed that her husband playfully accused her of being dominant, like her mom. Unfortunately, for the other women, the gender roles and norms they witnessed growing up in their families and the larger community seemed to be replicated in their intimate partnerships. They faced significant challenges in these areas; often reporting that they were unable to communicate with their partners on these issues. These women found it nearly impossible to refuse sex to their partners, ask them to use condoms or prevent them from having concurrent sexual partners. The exception is Liz, who was repeatedly sexually victimized and experienced severe physical violence which led her to seek safety in a domestic violence shelter. After receiving counseling at the domestic violence shelter and going through her own healing

process, she was able to change these dynamics in her next relationship and is now able to refuse sex, demand condom use, etc. Both Mary and Brenda Lynn have decided not to be in an intimate relationship at this time and Kiza remains married and continues to deal with these issues in her relationship.

When faced with physical, emotional and sexual violence, as well as physical and emotional neglect, the women in this study repeatedly mentioned that they believed this type of treatment was normal and, by extension, acceptable. Like Kiza, even when the women did not identify with a particular term, such as sexual violence, they were clear that it happened regularly in intimate partnerships. Prior to interviewing the women, the case manager informed me that many of the African immigrant women they serve have a husband with multiple wives and/or partners, and therefore even unwanted sexual advances are sometimes viewed by the women in a positive light as evidence they are still in good standing with the man. Situations like these are testament to how firmly the gender roles and norms of our youth can be internalized.

Cycle of Stigma and Silence

In the narratives the women shared, they repeatedly mentioned fear of having their HIV status exposed. In fact, the fear was so strong that a number of eligible women decided not to participate in the study at all. The women described fears of being seen receiving services at the AIDS organization and explained that is why many of them elected to not attend support groups. The women were particularly afraid that individuals from their home country, or almost any African nation, would find out about their status. When asked more about their fear they explained that many people gossip and there is a

lot of speculation about who may be HIV+. Conversations about this anxiety led to the root of their fear which was that people in the United States might tell people from their home community about their HIV status. The women in this study remained incredibly connected to their home communities; many had family members still living there, including parents, siblings and even children.

The stigma the women described was quite severe. It included family members not wanting to talk to them or touch them, even treating them like "lepers" for fear of being infected. The women attributed the high level of stigma due to lack of information or misinformation about HIV. Due to lack of access to treatment and medication, they also attributed the stigma to the association between HIV and death; stating that community members felt that HIV was a "death sentence". Mary, a self-described "God-fearing" woman, explained that HIV+ women in her home community are accused of being prostitutes. These accusations were extremely painful for her, a deeply religious woman who had never had a sexual partner other than her husband. Some of the women talked about coming to peace with their HIV status and so not wanting to have to put themselves through that painful process with their family now that they had finally come to grips with their status.

The women with children were also afraid that if their status was exposed that their children would be mocked and bullied. In fact, the women seemed more worried about protecting their children from being bullied. The women with daughters of marriageable age were also afraid that if their status was exposed, it would deter possible suitors for their daughters. Several of the women expressed that their children had already

suffered so much, especially Mary who escaped war with her children, and so didn't want them to suffer any more.

The fear of stigma was so strong that the majority of the women did not tell people of their HIV status. Most of them hadn't told anyone, except their case manager at the AIDS organization. The women who contracted HIV as children told their spouses and Michelle chose to tell her sibling and one of her husband's relatives, at his request. Only Liz, who has been through counseling for domestic violence and currently has an HIV+ partner, lives openly with her status. This silence seemed to reinforce the stigma the women face. Kiza mentioned that their community doesn't have a Magic Johnson-like figure who is open with his status. Michelle also mentioned that she felt it would be helpful for people in her community to see healthy individuals that are HIV+ so community members would know people can have full lives, even if they are seropositive. The women believed this fear of illness and death kept people from assessing their risk and being tested.

Some of the women also expressed a desire to keep the abuse they experienced secret, as well. This was especially true for sexual violence, which Kiza explained people often do not even consider as such, just something they didn't want to happen to them. Liz did reach out to a trusted family member when she was raped, but did not experience positive results. Instead of empathy, she was faced with disbelief and told to keep it to herself. This secrecy about violence, including sexual violence, that the women experienced may work to reinforce gender norms they internalized as children that violence against women is acceptable. These beliefs may, in turn, put them at risk for

contracting HIV because they may fail to protect themselves believing that their experiences are just part of being a woman.

RESEARCH QUESTIONS

Now, following overarching themes that were just discussed, each research question is reviewed and the associated sub-themes presented. The following findings were developed after engaging in narrative analysis to identify themes in the women's stories that shed light on the role of gender-based violence and inequality on the reproductive health and disease status in the lives of HIV+ African immigrant women. In some cases, the women's stories were summarized, in others their quotes or sections of interview dialogue have been included in full. An effort has been made, where possible, to include the women's full statements in order to preserve the richness and style of their responses to the interview questions. Please note that I have tried to reflect the participants' language as accurately as possible, therefore, grammar mistakes and other language issues have not been corrected. The study sought to answer the following broad research questions regarding HIV:

1) Do HIV+ African immigrant women describe experiences of gender inequality as part of their life experiences?
2) Do HIV+ African immigrant women describe encounters of gender based violence, including sexual violence, as part of their life experiences?
3) How do HIV+ African immigrant women describe their sexual decision-making?

4) Do HIV+ African immigrant women talk about contextual factors, such as poverty and migration, when they discuss their HIV status?
5) What do the stories of HIV+ African immigrant women teach us about HIV?

Research Question 1: Do HIV+ African immigrant women describe experiences of gender inequality as part of their life experiences?

For the purpose of this study, gender inequality was defined in terms of the social, cultural and economic inequalities women face and the role they played on women's vulnerability for contracting HIV. Factors of key interest included: family and community gender roles; household and relationship decision-making; and economic and educational opportunities. The narratives of these research participants highlighted the role of gender inequality in their lives, both in their families of origin, as well as in their intimate relationships. Their narratives showed the importance of family and community norms in terms of developing their sense of what is normal and acceptable in an intimate partnership. Their stories highlighted family structures in which the man's side of the family was often favored. For example, many new couples resided with the man's side of the family; when relationships broke-up children were often kept with the father's side of the family; and the father's side of the extended family often made decisions on behalf of the couple. The women's stories also revealed the different expectations and roles that were assigned to men and women. Their stories showed gender inequality in terms of the decision-making power women had within their families of origin, as well as their intimate partnerships, regarding critical family issues such as children, money and

employment. In general, women were socialized to be demure and acquiescent while men were socialized to have the ultimate authority in decision-making. These factors associated with gender inequality put a significant amount of pressure on women in terms of pressure to marry, stay married and have children. Finally, in contrast and as a counter narrative, the two women who contracted HIV as children mentioned growing up with strong mother figures who tended to have the most sway in family decisions. However, they stated this family dynamic was in contrast to the norms of the larger community where men tend to have this power.

Family Structure

"In my family, you marry, the husband took you to where he lives": The Influence of the Husband's Family

The women related stories about the structures of their families back home. The women experienced a wide variety of family structures, including having divorced parents, living with grandparents, and being unofficially adopted by older siblings. Some of the women described that when you marry, you are to stay with the husband's side of the family. Mary stated: "In my family, you marry, the husband took you to where he lives." One said they could go with either side of the family. Others explained that if they were older or had jobs they started their lives off together in a new place or where the husband had been living and working. Either way, the husband's family seems to have a continued influence on the couple and their future children; often making decisions on behalf of the new couple, their children and their careers. Marcia explained that, for example, if a husband had a rich relative, his family might decide it was in the couple's

best interest for their children to live with their wealthy relative. In that situation, the wife would not have the ability to refuse and most likely would be separated from her children against her will. Thus, we see a woman does not have full decision-making power, even with regard to the welfare of her own children. Sometimes, these decisions would go as far as arranging marriages. Liz explained a story in which a friend of her father raped her. She was unsure as to whether the father had given him permission to pursue his daughter, as was commonly done in her area. Sometimes these relationships led to arrange marriages and other times to sexual liaisons; in her case, non-consensual sex.

In situations in which marriages broke up, the norm for most of the women's communities was for the children to stay with the father and/or his side of the family. The reason behind this seemed to be the relative power of the husband's family, as well as the belief that men can better provide for their families financially. Mary explained the tradition as such: "Like a good man cannot leave kids. They can't go with the wife." She continued:

> Daddy responsibility to keep the kid because...man work and the wife is just someone stay home cooking. You know, doing stuff for… yeah. Now, men work and lady work, but in my time it was a little bit... wife was just for house, take care of house. Only men work. So, how you're gonna take the kids? You are not working.

"Then when he started having different women, things started changing": Fluid Nature of Marriage

Marriage figured as a very important institution in the lives of these women and figured prominently in their narratives. Nonetheless, their definition of marriage proved to be rather fluid. For example, they often referred to a couple as married even though an official ceremony was never conducted. Kiza explained it as something akin to common law marriage where the couple may live together, not be officially married, but be generally understood to be married. In other situations, the women explained that their husbands had multiple wives. This was the norm in their communities and the relations were often sanctioned by the community. In most of these cases, the husbands never officially married subsequent wives. Instead, they would develop a long-term relationship with a woman which involved sex, as well as the husband paying for the living expenses of the woman, her children and possibly even extended family members. Some men also had casual sexual partners; these were not considered to be marriages. But for many of them, it was a long-term relationship in which they would leave their wife and children for periods of time in order to attend to their other family.

Some of the women expressed the downsides and complications of families with multiple wives. Liz, who grew up in a family in which her father had multiple wives, stated:

> At one time, it was a good, you know, a good thing growing up with both parents. After some time my daddy had different wives and that was kind of hard on my

mom and on us. My mom, she worked so hard, you know, taking care of us and going to work and trying to make a living for us.

She described her family's financial decline as their resources were spread thinner with the addition of multiple families:

When we were with just my mom, things were good. We had clothes. We had shoes. In the neighborhood, we were the only kids who looked nice Christmas time, New Year's Eve. Stuff like that. Then when he started having different women, things started changing.

Liz explained that the norm she observed growing up of her father leaving for periods of time to look after his other partners and children, affected her in her future marriage in terms of her expectations. Thus, when her husband began disappearing for periods of time, she initially felt it was acceptable. Regarding her husband's habit of often leaving the home for days, she described:

(He would) just leave and go, sometimes he don't come home…. Mostly everything he wanted to do, he did. But I didn't really have many problems with him going and coming. I used to worry….I didn't know where he was. His coming and going, it didn't really bother me that much because I grew up around stuff like the. To me it was just normal.

Gender Roles and Expectations

"'Cause the girls gonna get married": Defined Roles and Expectations

Most of the women described families of origin in which both the mother and the father worked; whether in formal or informal employment. Nonetheless, the women were largely in charge of taking care of the families, in terms of preparing meals, tending to the home and taking care of children. Men were responsible for earning a living and making decisions for the family's well-being. Because of these expectations, as well as family structures that favored the man's side of the family, Kiza explained that most families in her community would prefer to have a male as their oldest child. This is because the oldest child is expected to help take care of the younger children financially. Gender role expectations promote this role being played by men. She stated:

> You know, back home, all because they always believe in the oldest person (child), they have to make it in life in order for them to help the other ones. Because if you miss, you know, your education, that means it's just like you forsake the whole family. Because everybody focuses on the oldest one and that's why most of the time, they want the oldest to be a boy, not a girl! 'Cause the girls gonna get married.

In contrast, Michelle described a different side to this situation although it reveals pressure on African women to bear sons. Her father initially wanted a son, after living in the United States, his thinking on the topic changed and he embraced his daughter taking on different roles. She explained:

> My dad would be like, 'Oh! I wish I had a son. Maybe I would feel like I belong.' Something like that…. I don't know. Well, I think my dad is different from a lot of African men. 'Cause a lot of African men, what they will do is, if they marry a woman and they don't have a son with her, they usually leave her and go find another woman, so they can have a son with her. Now, my dad, he had all girls. And, he always said, 'I wanted a son. I wanted a son.' What he did was, me growing up, he treated me like a son. I hated it, but I guess...like he taught me how to fix cars. He taught me so many different things, like how to fix lights and stuff like that….And now a days, he tells me stuff like, 'I don't want a son. Who said I want a son? I have you!' So, I laugh about it. It's funny, but it's different from a lot of African men because they will leave their wives if they don't have a son to find another person, even though it's not the woman's fault. It's the guy's (laughter).

"I used to do everything that I saw my mom doing": The Development of Gender Norms

The gender roles that the women observed growing up, affected their expectations regarding what was normal in intimate relationships. These norms guided what functions they performed for their family, as well as what behavior they tolerated from their husbands. For example, in describing her relationship with her husband, an American-born citizen, Liz explained:

> I was a stay-at-home mom. I used to do everything that I saw my mom doing, like cooking, taking care of my dad. Even when, you know, my dad hit her, did a lot of stuff to her, she would still get up and cook and be a wife. I thought that was normal. So I stayed in that relationship throughout being abused.

Concurrent partners. One of the main norms that the women absorbed growing up was that men are expected to have multiple, concurrent sex partners. In fact, most of the women described situations in which it was expected that the men would have concurrent sexual partners and that community expectations were that, as the wife, they would accept the situation. It was expected that the women would not end their relationships over this situation or even speak up against it. For example, Mary's husband was open about having concurrent partners. Other women reported similar experiences. Mary, she didn't feel she had ground to stand on to in terms of complaining about the situation to her husband because her basic needs were being met through the marriage. She stated: "If you try like complaining, because he have money, he say: 'You don't have food? You don't have clothes? …. You have everything!' He don't care about affection. So, we live like that because we don't have another way." Mary went on to describe a situation in which her husband even had her take care of the children he fathered outside of their marriage: "I was the wife. He was the man, African man. All the decisions. That's why he can go make baby and bring home."

"He makes decisions about everything!": Decision-making

All the women agreed that the tradition in their home communities was for the men to have the main decision-making power in the family. Kiza flat out stated: "It's the men that makes the decision. So, that's how it is over there. It's not like here. No. But now people are trying." Of her father's role in her family decision-making, Kiza said emphatically: "He makes decisions about everything!... Whatever it is, I mean, even if you talk about something, I mean, he is the one to have the last word." Examples that were provided in terms of male decision-making included decisions about finances and household purchases, as well as the care and education of children. Liz had a similar experience which colored her expectations in her relationship and what she perceived to be normal. She and I discussed it as follows:

> *Liz:* Being from (home country), most of the time, women, we don't really have our way. When I was with my (child's) dad, we didn't talk much. It's like, what he says goes. That's how everything was. What he says goes.
>
> *Joy:* So that was familiar from the way you grew up?
>
> *Liz:* Yes.
>
> *Joy:* So when it happened in your relationship...
>
> *Liz:* (interrupted) I thought it was normal. Until I came to America and I was like, 'Oh my God!'

In contrast to this widely held tradition, Brenda Lynn stated that in her home community, the decision-making process is quite fair. Although, she admitted that once a disagreement was reached, the process broke down:

> When they have some common thing to discuss they sit down together they discuss it together. They agree on that thing, they make the decision, take a position on what they want to do. But if they disagree, it doesn't work.

Brenda Lynn explained that this method is used in making many decisions, such as those regarding building a house or sending a child to school. However, she stated that if there is a disagreement between men and women on a decision, it may lead to fighting, including physical fighting. Usually in these situations, the man has the final say.

Mary agreed that in her community men made most decisions. Nonetheless, Mary stated that her step-mother dominated family decisions. This was not the norm in the community, however, she was able to do so because Mary's father had already divorced once and worried about his reputation if he divorced again. Therefore, her step-mother received greater leniency than was typical.

Marcia also experienced decision-making in her family that was not the norm, though she acknowledged that men usually made the decisions in her community. She explained:

> Specifically in my family, there is no difference between how a mother or a father can make a decision…. It was different in my family but in my extended family, I know that women cannot make decisions, even if they have the best idea. Men

decide if children go to school or if they get stuff, supplies. It's the husband who decides. It's the husband decides to sell the property, women have nothing to say about it. He just decides for her.

Michelle's family of origin also differed from her community in terms of how decisions were made. She explained:

My mom is very controlling (laughter). That's what I remember the most 'cause my dad… he was the only guy in my family… Everything we say goes (laughter). And he hated that. But as far as like when it came to working and making sure we have food on the table, my dad, you know, that's what he did. My mom, she was more of the one that made sure the bills were paid, or like made sure we had… you know, food cooked.

Michelle's parents currently own a company together. Michelle stated they mostly work as a team, however added: "But I think my mom has more of an upper hand (laughter). I keep laughing 'cause like it's funny." She continued by describing a change in her family dynamics after living in the United States and returning to their home country:

…my mom is the one that takes control. Like she feels like my dad can't do anything for himself. So, I think they are different. I don't know. It's like so different because I remember being in (home country) and it was never like that. It was more my dad's word was like, that was it! Whatever he says goes. But,

> then when we came here, it's like, the roles kind of...I don't know...I know there was a difference though. Like my mom was the one who said the final word. But it wasn't like that in Africa. But now that they are in Africa now, it's like 'cause they've been here, it's the same way. It's like she still has that… and when a lot of people, like a lot of African families, see that, they think that it's unusual.

Interestingly, even though both Marcia and Michelle grew up in communities marked by male decision-making, they each took after their immediate families when it came to developing their own decision-making style with their husbands. During her interview, Marcia went into extensive detail about how she and her husband make decisions and provided very thorough examples. In general, Marcia takes after her parents, as opposed to her community norms. She and her husband discuss issues together, collect information, take evidence into account, find compromises and come to agreements. Neither party dominates over the other. For example, she explained how she and her husband came to a decision about whether she should breastfeed her children as an HIV+ woman:

> Another decision is about breastfeeding. Because in my country...there was some criteria about if you want to breastfeed or not, even if you are HIV+. I thought I was in the category that can breastfeed, according to the way I was taking my preventive treatments, but the protocol in the US says there is no way you can breastfeed... My husband and I have to follow what the doctor said.

Similarly, the way Michelle's parents interact seems to have influenced her decision-making with her husband, an American-born citizen. She described their decision-making in detail as follows:

> It's funny because (husband) says I'm just like my mom. He says that I like to take control. I don't like to take control. I just feel like (sigh) like...ok, when it comes to paying bills, I'm usually the one who writes everything down. Writes all the stuff , you know: 'Pay bills today'. I pretty much budget everything. He can't do that, so I have to do that. That's not really taking control though. I don't see it as taking control. But he says I am more like my mom…. So, with our relationship the way it is, it's almost like…I don't know how to say this. It's almost like no different from my parents. It's like, if I say, 'We are going to eat this today'. This is what we are going to eat. And I even tell him, 'No! You can choose or you can pick what you want to eat!' He says, 'No, you said we were gonna eat this. We're gonna eat this.' That kind of makes me feel uncomfortable, a little bit. 'Cause I don't...I'm not a dictator (laughter)! I'm not a dictator! But that's how it is….He thinks the woman, she is supposed to like take care of things. But I tell him, 'You are the guy too'. When I grew up, my dad took care. I mean, he works. He works and everything, but he is more the one who lays back and I'm the one that tries to figure out the budget; how much money we have and where it's going to go. And then like, I will literally lay out a plan: 'Ok, this is for gas. This is for food.' And at some point, I feel like I am being a parent (laughter).

Or that I am dictating where the money is going to go, even though…I don't know.

She later continued: "But sometimes I feel uncomfortable because...I don't know, I feel like everything is supposed to be 50/50. But I guess nothing is really 50/50. Nothing. It's probably 70/something; 70/30." In terms of family planning, Michelle and her husband make decisions together, though she seems to play a keep role in these decisions, as the main factor affecting the timing of their children is Michelle's future academic plans.

"You are more respected in society if you are married": Pressure to Marry

As mentioned, gender roles and expectations, as well as family structures and decision-making styles placed significant pressure on women in terms of getting married, staying married and having children. Again, recall from above, that the concept of marriage here is fluid and that not all marriages are formalized. Oftentimes committed long-term relationships are considered and referred to as marriages. Sometimes pressure to marry was not overt, but came about because women often did not have a lot of options. For example, a difficult situation in Mary's home life growing up pushed her to want to marry to get out of the house, instead of continuing her education. To her, getting married was the quickest and easiest way to escape from problems in her family of origin and it often seems like the most viable option for women.

Sometimes the pressure to marry was related to maintaining a certain status in the community. Regarding the pressure to be married in her home country, Kiza stated:

Kiza: 'Cause most women, they never get that independent. Even if they have their education, they still feel like, you know, you are more respected in society if you are married than if you are not. Even though you have a good job, you have whatever. If you're not married…(pause)

Joy: It sounds like there is a lot of status that comes from a relationship, so there is so much pressure to keep that relationship. Be in a relationship, then keep the relationship. Is that true do you think?

Kiza: Yes, it's true.

In Kiza's opinion, pressure and/or desire to marry has important implications for the spread of HIV because it can make it difficult for women to ask their sexual partners to use condoms. Thus, in these situations, a woman may decide that it is more important to be seen as "marriageable" than to protect her reproductive health. Thus, it seems as though the high price of marriage was the acceptance of traditional roles, sometimes including sexual abuse and coercion by men. We had the following exchange on the topic:

Kiza: …You know, it's just like, if I don't do what he asks me to do, maybe he's not gonna marry me. So, you have that pressure. So you just, sometimes you don't want to ask because you just want to make them comfortable. Even though you know you might end up getting sick. But you just say… 'whatever.'

Joy: 'Cause it sounds like there is a fear that you could lose a relationship just

based on asking that question? It could raise suspicions?

Kiza: Yes. It's just like, 'Well, you don't trust me….da, da, da, da, da…'

In discussing this issue with the women, one of the women stated that if a woman has a child, the pressure to marry is even stronger. Nonetheless, she was able to overcome this situation and called off an engagement to a man who was the father of her child. She called off the engagement shortly before the wedding even though many people were angry with her. She stated: "We were engaged, but I had the guts to say 'No' because there were certain things I didn't like." Our discussion on the topic shows her strength and courage:

Participant (deidentified): Well, it was a huge pressure, but I did handle it well. That's all I can say (laughter)! That's why I don't see it as a big issue because I did handle it well. Because if I couldn't handle it well, it would be like… but I handled it very good (laughter).

Joy: Good for you! Good for you!....

Kiza: Yeah, but if I was back home, maybe it wouldn't happen, but you know…

Joy: But here you were financially independent and?

Kiza: Yeah, I was working, you know. You know, I had my education. I was like, 'Forget you!' (laughter)

Joy: Right, good for you! (laughter)

Kiza: And then it was over!....I said, 'Goodbye! Next!'

"If my mom can stay, I can stay too": Pressure Not to Divorce

The pressure on women does not end with getting married. Women are also pressured to stay married. Oftentimes these norms regarding preserving the family were observed as children and then put into place as adults. In general, the pressure to stay married was much stronger for women than for men, regardless of the situation leading to the divorce. When asked whether she felt there was pressure to stay married in her home community, Liz responded that there was pressure, even in situations involving intimate partner violence:

> Yes, there is. Because I saw my mom, she stayed through all that. Sometimes, my daddy, he would leave for no good reason at all. We would try to stop him. We would crying and pulling at him and he would turn around and whoop everybody in the whole house. Mommy is over there with pink eye or bruises on her and we are in the corner crying like crazy. And she stayed. She didn't go nowhere. She didn't tell anybody about it. I am like, if my mom can stay, I can stay too. And she said she stayed because of her kids. And I felt like I had to stay because of my (children) and it was like, 'Wow, I don't believe that any more.'

When talking about men cheating and having multiple partners and whether women can leave a relationship because of that situation, Kiza explained that, in general, cheating is not an acceptable reason for a woman to divorce her husband. If she does divorce her husband, she will be the one who looks worse in the community's eyes, even

though he is the one who was unfaithful. Kiza and I had the following conversation on the topic:

> *Kiza:* Sometimes they suspect (their husband is cheating), especially the wives. Even if you know, what are you gonna do? There is only one thing that you're gonna do. It's divorce. And you know divorce is not, I mean people they start doing it now more often than before, but people, they don't. You don't just divorce just because you are suspecting something or because he's messing around with somebody else!
>
> *Joy:* It's not an acceptable reason for a divorce? What would be an acceptable reason?
>
> *Kiza:* Hmm (pause). More likely it's the man that leaves the woman than the woman leaving the man.
>
> *Joy:* And what is the usual reason for the man to leave the woman?
>
> *Kiza:* Well, they're just gonna make up a story like, maybe you are possessed! Or…you are in witchcraft. Or they just make up… 'Oh, she has been cheating on me!' And most of the time, you know it is a lie. But because they just want out.
>
> *Joy:* Why do you think they want out…?
>
> *Kiza:* Well, maybe they just want to because they found someone else. Or maybe they just want to because they want an easy way, an easy way out.
>
> *Joy:* But, so women don't leave the men very often? So, it sounds like there is a lot of pressure on women and it sounds like there is a lot of fear about losing your

partner. Like if you were to say no to sex or ask to use a condom or other things, you could lose your partner?

Kiza: Yes. Because when the divorce happens, even if you as the woman, you were right, but the fault always falls on the woman.

Joy: In the community's eyes?

Kiza: Yes. Because you know, they really don't look at the man like… They can see that the man did something wrong. They see it. But it's you, people are gonna look at you different: 'You know, she is bad! She's been divorced!' You know, some of them (women) divorce and they get married again, but just a few. But most of them, it's just like maybe you have to change cities. Go somewhere else, probably. Yeah, but if you stay in the same community and you leave this man here and someone else wants to marry you, that's very seldom.

Joy: So, you don't want a reputation. A woman doesn't want a reputation as someone who leaves a man because even if people know he's been cheating, it was wrong for her to leave for that reason?

Kiza: Yeah, but you are the one who's gonna look bad. The man doesn't look bad if they've been cheating, you know, so it's always the woman who looks bad.

Joy: So, it is accepted in the community that men can cheat? That they will cheat?

Kiza: Not acceptable because women do suffer from it. But they just don't have, I don't know what I would say, it's not a power, but they just don't have the guts… you know. They know and they're hurt but they're just there!

Mary described a bit of a different situation. In her community, she felt that men can also face judgment for divorcing, though it is not as strong as that for women. Women face judgment for being divorced at all. Men only face judgment after having divorced multiple times. This is the situation her father found himself in after her mother left due to his cheating. Furthermore, Mary explained that having a divorce in a family can affect the reputation of the whole family and even affect family members' marriage prospects. Her explanation was as follows:

> *Mary:* You know, when a man divorce for the first time, if he marry for a second time…I can explain his good in French... He is like, now it is a shame for him to divorce again. So, he prefer to be quiet for everything, for not to go to divorce again. Even it was very hard for him….
>
> *Joy:* So, there is shame in divorce. Even for men?
>
> *Mary:* Even for men. It is like, 'Two times?! You are not a good person.' Even in your family, people divorce. Sometimes in some family, before he can marry my daughter, he has to ask, 'Is there divorce in this family?'

On the other end of the spectrum, Kiza explained the concept of marriage in a more fluid manner similar to common law marriages marked by the couple living together. Because of this fluid nature, she explained that if a couple has problems, they are able to split and get new partners. She did not see stigma against "divorce", whether formal or informal, as a major impediment to ending a relationship. Brenda Lynn explained a similar situation. In her community, she felt women are often dependent on

men financially and that there is significant pressure to be married and stay married (even if it is unofficial), but it is possible to leave an unhealthy relationship. Nonetheless, she said that women sometimes stay in the relationship because they love the husband; they don't want to be separated from their children; or they are financially dependent on their husbands. She explained as follows:

> *Brenda Lynn:* In our village if you are married, we always have problems with your husband all the time. It's possible to leave.
>
> *Joy:* It is possible?
>
> *Brenda Lynn:* Yes it is possible. I don't have any problem about it. You can leave and your husband can get married to another woman.
>
> *Joy:* You don't even have to get divorced?
>
> *Brenda Lynn:* No, you just leave. You can still leave him and marry another man. Not everybody in our village gets married officially.
>
> *Joy:* So, you're not getting married officially, just living together?
>
> *Brenda Lynn:* Some can have ten kids and not legally married. So, when any problem comes, you can go and the man will marry another woman….
>
> *Joy:* So, there is not a lot of pressure to stay married if you have a problem? Your family and neighbors will say that it's okay if you left?
>
> *Brenda Lynn:* Yes, if the marriage is not working you can go. You can leave.

"You just marry for kids, for making kids!": Pressure to Have Children

Many of the women who participated in the study also faced pressure to have children. However, the pressure was so deeply ingrained in the culture that it often appeared subtle, as childbearing was seen as a natural and necessary part of long-term relationships. With the exception of the two youngest participants, and Brenda Lynn, the women did not describe actively planning their families, instead children seemed to be viewed as a natural outcome of intimate relationships. Mary stated: "You just marry for kids, for making kids! (laughter) (pause) Because if you marry and you don't make kids…Big thing is when couples marries, no kids. The first they say, 'Is the lady.' Now we understand that men cannot… Yeah, you know? (laughter)" She goes on to explain that people will often encourage the man to divorce the woman in that situation even without knowing the source of the couple's fertility issue. Michelle stated the same was true if it was believed that a wife could not provide her husband with a son.

For Brenda Lynn, the pressure to have kids was more explicit. Her husband expected her to have a child every two years. She also explained that other families in her community had the same expectation. Once her husband completely stopped providing for her family financially, she began to fear having more children and, therefore, began refusing to have sex with him. She also began taking birth control pills secretly. She reported that many other women in her community also took birth control pills secretly because they believed it would lead to an argument with their husbands who wanted them to continue having children.

Research Question 2: Do HIV+ African immigrant women describe encounters of gender based violence, including sexual violence, as part of their life experiences?

As with most women around the world, these women lived in a context in which violence against women was normalized. Unfortunately, the majority of the women in this study experienced multiple forms of gender-based violence. Their narratives reflected the difficulties women face in saying 'No' to sex, especially with marital partners. They also revealed experiences with sexual violence at the hands of husbands, family members, and community members, even leading to a rape-related pregnancy. The women also reported physical and emotional abuse by husbands and partners. In addition, these women experienced physical and emotional neglect by partners who prioritized their own desires above the basic needs of these women and their children. The two exceptions to these experiences were Marcia and Michelle who both contracted HIV as children and later married very supportive husbands. Although, as a practicing doctor, Marcia was very aware of these forms of violence in her community even though it wasn't her personal experience.

"I am gonna tell you, we don't call it rape": Sexual Abuse

With the exception of Marcia and Michelle, who were infected as children, the other four women experienced multiple forms of sexual violence perpetrated by various individuals. Some of these acts of violence were fueled by a belief that rape cannot occur within a marriage or intimate relationship. Regrettably, the times when the women reached out to others about their victimization, they were either not believed or were told to be quiet. Sexual violence was rampant in many of the communities from which the

women came. Although Mary's husband was not sexually abusive, nor did she witness it in her immediate family, it was prevalent in her community. She said: "Yeah, if the wife don't like it (sex), he beat her. He force her. But in my country, we don't know about calling police. Nothing."

Some of the women spoke about the fact that terms such as "sexual violence" or "rape" were not accepted in their community. Kiza was quite adamant about how strong this attitude is in her community. She said: "I would say like, sexual violence, most people from Africa, they are not going to tell you about it. So, you won't know." Kiza's views on sexual violence were very telling. In her responses, she was quite insistent and clearly wanted me to understand, thus, often eagerly interrupting me before I could finish the question. The following was our dialogue on the topic:

> *Joy:* And sexual violence, like in the United States, we think of it, we often think of rape and things like that. But it's also…
>
> *Kiza:* (eagerly interrupting me) I am gonna tell you, we don't call it rape. Even if you have, you tell your parents, they will just tell you, 'You better…. You don't… There is no rape here. He is your husband and you don't call it rape.' And when we hear it on TV and people are talking, we don't call it rape.
>
> *Joy:* So now, in the US, we are trying to understand not just rape, like you are saying, because a lot of people don't identify with that word. But a lot of times people have experiences, sexual experiences that they didn't want.
>
> *Kiza:* (eagerly interrupting me). We all do! We all do.
>
> *Joy:* With partners and husbands?

Kiza: Yes. We all do (pause). But since it is your partner or whatever, you don't call it 'rape'. So, you cannot go somewhere and say, 'He raped me.' No, how can he rape you because… no. People over here, they won't understand that. But people from my country know, you cannot call that rape.

Joy: So, how would you define it? That experience with a partner or husband?

Kiza: Well maybe you would call it, 'Oh, well, he just forced me to do something that I didn't want to do.' But you are not going to call it rape (silence).

Joy: Ok. And do you think it is very prevalent? Do you think it happens a lot?

Kiza: Yes, a lot!

Joy: But people just…

Kiza: (finished my sentence) don't talk about it.

Joy: For example, if a friend of yours had an experience, do you think she would talk to you about it?

Kiza: No.

Joy: And you wouldn't talk to her either?

Kiza: No.

When interviewing Brenda Lynn, she readily told me about her experiences with sexual violence and openly acknowledged that what she experienced was rape. She explained her experience with sexual violence at the hand of her husband in vivid, expressive language. She launched into a description of her experience before I inquired

about sexual violence and was first trying to learn about her sexual decision-making with her partner. The following dialogue ensued:

Brenda Lynn: We used to fight in the nights. Would fight the whole night sometimes before he could have sex with me.

Joy: He wanted to have sex and you didn't?

Brenda Lynn: I didn't want to. He couldn't even have me to do anything. We would fight. I can be strong like a man.

Joy: So you would yell and quarrel and physically fight and then what would happen?....

Brenda Lynn: He was stronger than me because he would pull on your pants like this (motioning with a downward action) and then cut (rip) it off. Then he would have sex with you and you can't say anything.

Joy: So some women have a hard time saying “no”, but you could say no to your husband?

Brenda Lynn: I used to say ‘No’ but he is stronger than me. He is a tall man. I couldn't fight him. Sometimes I would just get out. I would run.

Joy: Even in the middle of the night?

Brenda Lynn: Yes. One time I left my house and just underwear to a friend’s house and I slept there until the next day.

Joy: When you were unable…when you could, you would run away?

Brenda Lynn: Yes, when I could I would ran away.

Joy: So, he would basically be stronger than you and overpower you and then force you to have sex?

Brenda Lynn: Yes….

Joy: Did that happen for many years?

Brenda Lynn: No, just sometimes. It happens about just six months, so I decided to leave.

Joy: Was that your main reason for leaving?

Brenda Lynn: Yes, I didn't want to stay with him anymore because he's not helping me, he's only trying to have sex with me and I couldn't stay, so I decided to leave.

Joy: You are in the relationship and he wasn't helping you, but he would want to have sex with you, so you would not want to have sex and he would force you?

Brenda Lynn: Yes

Joy: Earlier in your marriage, before that happens, how would you make decisions about sex? Was it different in the beginning?

Brenda Lynn: No, in the beginning it was just an easy thing. He loves me, I love him. We would just go to bed. If you want to have sex you pull off your own clothes. No problems. It came to that time that he didn't want to help me, I used to go to bed with no clothes but when I didn't want to have sex, I would wear my clothes really tight and come to bed that way. We would fight.

Later in the interview, she explained that despite issues with money and physical violence, it was the sexual violence that convinced her to leave her marriage and, thus, subsequently become separated from her children. She described the situation to me as follows:

> *Brenda Lynn:* …The only problem that made me to leave was just sex; the sex thing during the nights….The sex is what made me just leave the house because in the night I couldn't sleep. Every night I would just leave.
>
> *Joy:* This was happening every night?
>
> *Brenda Lynn:* Every night.
>
> *Joy:* For a period of like six months you said?
>
> *Brenda Lynn:* Yes, six months because this is somebody who drinks every day. If he doesn't drink he will sleep quietly. But when he drinks, he come back and I must have sex with him. And if I don't, then we fight. So I said 'No, let me just leave'.

Liz also had a troubling history of sexual violence, though the violence she experienced was perpetrated by more than one individual and started at an early age. Liz also spoke openly and readily about experiencing sexual violence, getting visibly emotional while sharing her experiences. She explained that as a child, she was raped by a member of her extended family. As a teenager she was raped by a trusted member of her community. Then at the end of her high school education, Liz was raped and became pregnant. She dropped out of school and never finished. She had the child who was

eventually adopted unofficially by a family in her community because she was unable to take care of the child at that time. None of the men in these situations were held accountable for their violent behavior. What made the situation even worse was that when she told her family about her experiences and reached out for help, she didn't receive it. She stated:

> … nobody believed me. I remember it was so bad because they said, you know, I did that to myself, without trying to investigate and see what really happened. It took me a long, long time just to open up and say a lot of the stuff that happened to me when I was growing up. I went though some changes in my life…. The life that I had, it was a rough life.

Liz described a final incidence of sexual violence perpetrated by a friend of her fathers. She explained that men in her community sometimes gave their friends permission to pursue their daughters for marriage. These arrangements were not as structured as other arranged marriages. Sometimes they led to marriages and sometimes they didn't. However, either way, the arrangement seemed to grant the friend carte blanche. It sounds as though this practice was often undertaken without the daughter even being told, let alone asked for her opinion. Interestingly, when I asked if this was a consensual arrangement, Liz stated that it was consensual; but she meant with the woman's father, not the woman herself. This highlights the prevalent thinking that men have the ability to make decisions regarding women and their well-being including their sexual health. She also used the term parents when describing the practice, so it may be

that some mothers are also aware of this process. Liz explained her experience with this practice as follows:

> *Liz:* Yeah… They thought it was okay. My daddy, he had young women, friends' daughters and stuff, so they thought it was okay. If he can be with his daughter, then they could do something to his daughter, I guess… I don't know.
>
> *Joy:* Your dad was with his friends' daughters?
>
> *Liz:* Yeah. A lot of his friends' daughters or sisters, just some young women.
>
> *Joy:* But consensual, with their permission?
>
> *Liz:* Oh yeah, with the parents' permission.
>
> *Joy:* So the parents knew?
>
> *Liz:* Yeah. And I don't know if my daddy knew, or he talked to his friend about it. I don't know. I feel like he knew about it, but he never said nothing to me, so I don't know. But it happened…

Later in the interview, I came back to this story to clarify that I understood the practice correctly and Liz further explained:

> *Liz:* It's just like, if you have a friend and like your friend's daughter, you talk to your friend and say, 'I would like to marry your daughter. I like your daughter.' You talk to the father to say 'Yes' or 'No'. So, when the father says 'Yes', sometimes the father talks to the mom and daughter. But some, they don't do that. As long as your father says it's okay, the guy comes whether you like him or not. Your parents said 'Yes'. You have to be with that guy. It's like arranged

marriages, but if you are not married, they use you or just be with you and let you go.

Joy: So they don't always marry you?

Liz: It depends on…most of the times it depends. Most of the time, they want to marry five to six women. But if they feel like they don't want to marry you or you are not good enough for them, they just leave you alone.

Joy: So, usually they would tell the parents, 'I want to marry your daughter'?

Liz: Yeah, like 'I want to marry your daughter'. Then he tell him, 'Okay this is what I want; maybe you bring me two goats or some clothes or some money…

Joy: Like a dowry or…?

Liz: Something like that. Then we do it like traditional wedding. Then they bless their daughter and she goes. And sometimes it happens like that; like 'I like your daughter' and you let your daughter know. The guy is coming on to the daughter talking and stuff like that. From here everything goes.

Joy: And they don't necessarily have to marry you? So, sometimes your father would do this but not marry the woman?

Liz: Most of the women my father was with, they were all his wives.

Joy: Okay.

Liz: Only a few that I know he was not married to them. But either he had kids with them, or he just left.

Joy: So you were wondering if your dad had maybe made some kind of arrangement with him?

Liz: That's what I was thinking. But I can't say it was true because it happens a lot. So, I can't put two and two together. It's just a thought I had in my head.

Joy: The issue of marriage never came up?

Liz: No. It's too comfortable. You just get too comfortable. It's just like it happens, 'Are you serious?' Then, I didn't think it was that bad, like I do now. But everything was just normal because it was like… whatever I learned at home, that's what I knew.

Joy: Right, of course.

Liz: I don't want my kids to be like that.

Finally, even though Marcia never experienced sexual violence, she was very aware how common it is. She stated:

> I have a lot of stories. In my family I saw my mother being a victim of sexual violence. In my career I saw people, victims of violence. Unfortunately, I have a lot. Personally, I am lucky. I did not have this kind of experience. In my country these kinds of things happen unfortunately. I can say every day, maybe every hour.

Marcia gave a detailed narrative about one of the first examples of sexual violence and exploitation she witnessed. The story also gives a glimpse into some of the dynamics leading to the continued spread of HIV. Marcia's family had a young live-in nanny who became pregnant. As it turns out, her pregnancy was the result of sexual

assault committed by a member of Marcia's family, thus one of the young nanny's bosses. Instead of holding the perpetrator accountable, the nanny was sent away because she was not family. As the father's family has the traditional responsibility of taking care of children, the child stayed with his family. It later turned out that the baby was HIV+ and died. Her family tried to track down the nanny to let her know she was HIV+ but she had remarried and they never found her. Thus, not only had the family member sexually assaulted her, but he most likely also transmitted HIV to her. Marcia concluded:

> It was my first time to see how people can be abused and how it can affect their life; that it can affect their whole life. Maybe she will never know. I don't know if she's still alive or dead. I don't know if she knows she had HIV, or maybe she transmitted it to her kid and her new husband and so on and so on.

"He wants to do this, I have to do it whether I like it or not": Saying 'No' to Sex

As Kiza mentioned, there is a widespread belief that women cannot be raped by their intimate partners. Additionally, there is significant pressure on women to satisfy their partner's sexual desires as part of their duty as a wife. There is an associated fear that if you don't please your husband in this manner, that he will leave you or you will lose his favor. Thus, many women of African origin do not relate to the words "rape" or "sexual violence" and may not view themselves as survivors. Therefore, discussing whether or not women are able to say 'No' to sex, may provide a more accurate understanding of the issue. Again, Kiza helped clarify this phenomenon:

Joy: Can you tell me of any experiences you have had or any other friends or family members have had in terms of not wanting to have sex?

Kiza: See because the way we were brought up, they will give you this scripture in the Bible all the time, so it sticks in your head, 'Do not deprive one another.' So, it's already in your head because they tell you once you get married, you need to know that. And if you say 'No', it's something that creates conflict, you know, in a marriage. But I mean, if you say like, 'Not today, not tomorrow,' they will go and find a…how do you say it?: 'A chick on the side' just to make you jealous because you don't want to give it up.

Joy: So, it sounds like you've been told not to. So, there is pressure. Is there more pressure on the woman?

Kiza: Yes.

Joy: Ok, so, there is more pressure on the woman to not deny their partner.

Kiza: Yes, there are men who say, 'No'. But the woman… The man, when he's tired, doesn't feel like it, he says, 'No'. He says, 'No'. You cannot pressure him. But if it is the other way around…

Joy: And so, there is also fear that if you say, 'No', they'll find another partner?

Kiza: Yeah, or they will be mad at you for a few days. So, you just don't want that to happen. And then you just (pause)...even if you don't feel like it.

Many of the women also expressed barriers to saying, 'No' to sex. Or if they could say, 'No' to sex, there were strict circumstances in which that was acceptable. For

Mary, she stated that she could say, 'No' to sex when her husband was away all weekend with another woman because she described that having sex with him in that situation would have been "dirty". Several women mentioned sexual advances on the part of a husband as a sign of favor (even if they were unwanted); something that was desired because you wanted to maintain his interest given his multiple partners. Mary stated it as such: "When I am upset, I say, 'No'. You know, when you say 'No' and he's not insist, you know that he have another person. But when you say 'No' and he is mad, that means he don't have another person."

Liz explained that if you say, 'No' to sex, your partner may accuse you of cheating. Brenda Lynn stated the same. The same can also happen when you ask him to use a condom. When asked about whether she was able to say, 'No' to sex, Liz stated:

> *Liz:* If I said, 'No', it's like you are saying, 'No' because you have been messing around with somebody else. It's like I'm just there. I don't have no decisions to make for myself or nothing.
>
> *Joy:* There was no force involved or anything like that, it was just…
>
> *Liz:* Not really, it was just when he says 'It's time', whether I like it or not, you have to obey and do what they ask you to do.
>
> *Joy:* What would the consequences be, if you said, 'No'? He would accuse you...?
>
> *Liz:* Of doing something else.
>
> *Joy:* Any other consequences?
>
> *Liz:* Just talk a lot and just… I didn't have a reason to say, 'No', it was just like, okay. He wants to do this, I have to do it whether I like it or not. I can't say, 'No'.

Joy: That was part of marriage...?

Liz: Yeah, marriage, boyfriend/girlfriend, just the same way. It's like, men, they have the power over women. But here it's like 50/50, or at least the woman has a say in the relationship. We didn't have much say.

Joy: So, you feel like it's the same even if you're not married? Even if it's just a relationship with a man? The same issue about not being able to say, 'No'?

Liz: Yeah, if you are like in a committed relationship, you have to be there, do what the man say do.

Joy: Do you have any more power if it's not a committed relationship?

Liz: I don't know because I have never really been in one like that.

Unlike the other women's experiences, Liz stated that she was able to say, 'No' in her marriage even though it eventually became physically violent. She described how they negotiated sex:

> When I was with my husband before we got married, I didn't have any contact with him like that. He tried, I said, 'No, we need to get married and that's when we get into that'. When it was time for us, we have to, you know, talk about it. We had our own way of saying, 'Okay this is now time'. If it's on my time or his time, we know how we had to do something and we talk about it. We both agree. If we were on the same page, we do that.

When asked what made the difference for her in terms of being able to safely negotiate when to have sex in the United States, she stated:

> You know, just coming here, watching TV mostly, and learning more about the culture here. The women have rights. They have a right to say 'No' in a relationship or anywhere else. It's okay to say 'No'. And I was like, 'Wow'. It felt good, and the first time I said 'No', I felt like, 'Oh my God!' It felt like the weight just came off me like that. It was easy to say 'No', and it was okay. I didn't have to feel guilty about it.

Happily, in Liz's current relationship, she is able to say, 'No' when she doesn't feel like having sex. This process is eased by the fact that her partner is also HIV+ and so they have experience talking openly about their sexual health. She stated:

> It was like, it was something like, if I don't feel like it, I don't feel like it. If he gets mad, at least I feel like I had a say when it comes to that. I didn't feel like somebody had to force me or I had to do something I didn't feel like doing. At least I feel like I could say, 'No' and its okay to say, 'No' because I didn't know how to say, 'No' (before).

She later continued about what it was like now to have conversations with her partner about whether or not to have sex. She described:

> Yes, it is very, very easy with him and me. We argue. We don't get along sometimes. But when it's time for us to be like that, we know, we talk about it. Or

> if we don't talk, just actions and we know how to be around each other better. If he tells me, 'I am tired, I don't feel like it', I am not going to be mad. I will feel bad, but I am not going to be mad. If I tell him the same thing, sometimes he gets mad. But not that bad. He understands. So we understand each other better.

"Wow, I didn't know that was abuse!": Physical Abuse

Liz, who experience violent sexual victimization as a youth and severe physical abuse in her marriage explained that she felt intimate partner abuse was normal. Liz experienced severe physical abuse at the hand of her American-born husband. The abuse, which was eventually turned against her children as well, led her to seek safety in a domestic violence shelter and to obtain a protective order. When asking Liz about herself, after stating her age, number of kids and marital status, she immediately told me: "I had to leave my husband because he was very abusive; I have been through a lot you know. When I was with him, I had to go to the shelter, stayed there with my kids." Of her relationship with her former husband, she stated:

> He would go, come back. People told me he was using drugs, but I didn't know until I saw him myself one day. He was so upset because I walked in on him. I said I didn't know what he was doing. Then he started changing little by little, bringing women to the house (stating) 'they would give me a ride… my car broke down…' I kept a lot of things to myself, I didn't talk about nothing and nobody from the outside knew what was happening…. I will say I thought it was okay until I started watching different shows; seeing this abuse, and I was like, 'Wow, I

didn't know that was abuse!' So, when he hit me, he used to hit the (children) when they went to school. I didn't know a lot about what was happening. Then people started telling me and somebody called CPS because he was yelling at my (child). They came and did the investigation, they left, and somebody else again called, so they came. And when he hit me, I was scared to tell the police that he hit me. I just said somebody else did. Then after some time, after I came from the hospital, I had to call the police and just let them because it was just…we kept on saying, 'Stop!' You know, it was scaring me, so I told them what happened…. They came and asked me what did I want to do. You know, they gave me two choices: stay with him, or they would take the kids. I said, 'No, these are my kids'. I had to choose my kids and I lived with my kids. That's how I went to the shelter. From there, he tried so hard to be around me. He wasn't supposed to know where I lived when I moved from the shelter, but he found out anyway. He kept on coming, threatening me. I had a protective order.

Liz explained that the violence she experienced had emotional repercussions and affected her sense of self:

My self esteem was so like down. It's still kind of, but I am learning how to feel good about myself. I used to be real skinny when I came back home, that was my normal weight. All this crazy stuff going on in my head, I started eating more than I was supposed to. I gained a lot of weight…. I just didn't care. I didn't feel like I was good enough for anything; just to stay home and do nothing.

After threatening her again and breaking the protective order, her ex-husband was briefly jailed. Happily, since her experience living in the domestic violence shelter, Liz seems to have gone through a transformation in the way she feels about herself and her relationships. She described the transformation, which she has maintained, as such:

> Since then, you know, I don't like anybody abusing me… It's hard for me to be in a relationship. I don't like anybody telling me, like being loud with me. It just takes me back to all that stress I have been through. Like right now, I enjoy my kids being in my house, no one telling me when to go or when to come. It's good like that.

The physical violence Brenda Lynn experienced was directly related to her experience with sexual violence. She explained that her husband would physically beat her when she would refuse to have sex with him, then he would rape her. She stated that he would also beat her when she went out with friends to drink and would stay out late. Brenda stated he had a large drinking problem and would also harass and beat up strangers on the streets. She said the alcohol "made him fight too much with me." She declared that she believed this kind of violence was normal because "when you went to tell your other friends, she would tell you the same thing…" She explained the nature of the violence he inflicted upon her:

> I would just open the door and he would start hitting you like that. One time he hit me with an iron like that (motioning downward) and I fell down. I was unconscious. He laid me down on the bed and left me there. I lived there for some

> time and then I woke up. So, I had to run that night to my friend's house, to other people's house, and stay there until the next day. Then he would come down there and begin to beg and plead, say it was because he drink too much. It was because of alcohol and asked me to come back to the house.

Not all the women witnessed intimate partner violence in their families, though violence against women seemed to be a common feature in their communities as a whole. Marcia astutely observed the high rates of gender-based violence in her country and recognized the overlap between different forms of violence. She stated: "Physical violence, most of the time it goes together (with sexual violence). People don't say that, but it goes together. Physical and sexual violence goes together in marriage." She later continued with regards to emotional abuse: "I think it goes together, if you are sexually abused, you are emotionally hurt psychologically. It all goes together." She stated that she feels it is especially terrible to see family members abusing other family members, but it happens and she believes it is because people "…want to show power and they show that by violence, sexual or physical," against people they perceive as weaker. Mary did not witness intimate partner violence in her immediate family, though she saw it in her community and in her extended family. She shared a story in which her cousin's husband beat her every day. After almost 30 years together and eight children, he told her "I think you not the wife God make for me" and beat her so brutally she died of her injuries a month later. Thankfully, Kiza explained that more women in her community are talking

about physical violence and have even begun calling 911. Perhaps then norms around the acceptability of physical violence are beginning to change.

"He said he did me a favor to take me in with my (children)": Emotional Abuse

Kiza stated that emotional abuse is very common. She described emotional abuse as such: "They will say things or do things to you that it's horrible! And you just don't know where to go." Nonetheless, she added: "It's gonna make you mad. But you don't have anything to say." She further related that she believes it's not possible to intervene with friends experiencing emotional abuse. She said: "Cause you cannot get involved in someone else's relationship. And even if you talk to a woman, she might end up telling the husband. And you might get in trouble with the husband. He won't want to see you around." Unfortunately, this is a deterrent for women to help each other through these situations and overcome attitudes that say it's acceptable.

One of the women experienced emotional abuse and intimidation due to her lack of documentation. This made her feel as though she wasn't able to live and function without her partner. Our discussion on the topic followed thus:

> *Participant:* He would say, you know, there's nothing that I can do since I had no papers, and nothing tha**t** I can do. And nobody is going to want me out there with (children). He said he did me a favor to take me in with my (children). And that just like, 'Oh my goodness'. I didn't think anyone would look at me and say anything. It stayed with me for a long time.
>
> *Joy:* He had you convinced of that?

Participant: Yeah, and I was scared to even leave. I didn't know I could just get up one day and say 'Enough!' and just go somewhere. …I didn't think I was ever going to leave because I felt it was my comfort zone right there with him. I felt like without him I was lost. I didn't think I could do without him being around. Even when I was on my own, I felt like that for two or three years.

Joy: After leaving him?

Participant: Yeah

Joy: Was it mostly financial or because of your...

Participant: (interrupted) Everything. Yeah, everything. I was like, 'Oh my God. I have to learn to live by myself. What am I going to do? How am I going to do it?' I did not know how to do that on my own.

"I would ask if he had money for food. There was no food": Physical Neglect

When discussing child protection issues, we often hear about abuse, as well as neglect. However, when discussing gender-based violence and intimate partner violence, we rarely think in terms of neglect. Nonetheless, these women's stories highlight issues of physical, as well as emotional neglect and reflect the tangible effect they have on their lives.

For example, although he had a steady job, Brenda Lynn's husband refused to share his wages for the support of the family. Instead, he would use the money to fuel his growing addiction to alcohol. She explained:

> I used to go to my friend's house. I had a friend at one time that would help me…I would go there and she would give me food. Then my kids would get to eat and I wouldn't care if he got to eat it all. When he would come back, I would ask if he had money for food. There was no food. Then maybe we would fight again. He wants his own food. If you don't bring food for him back, he will beat you until you have to run away from the house.

At the beginning of their marriage, he would reluctantly share some of his wages after a friend or neighbor intervened on Brenda Lynn's behalf. However, at the end of the relationship, he flat out refused. This led Brenda Lynn to fear becoming pregnant. Liz also experienced physical deprivation due to a partner's neglect. She related that she and her family lived without running water, electricity or gas in their home for a period of two year. Eventually, a faith leader gave her money to have the services turned on. Meanwhile, her husband was spending money on his drug addiction. Both men had multiple, concurrent sex partners. Relatedly, these women also related stories of growing up in which their family's financial stability was threatened by their father's acquisition of multiple wives and partners, thus, perhaps for a time they felt these situations should be endured.

Unlike in mainstream United States society, it is the norm for African men in many communities to pay for the living expenses of the women with whom they are having sex, even if they are not officially married. Mary stated: "Oh yeah! If you take them, you have to support them everything." She continued: "Children or not children,

you support. You buy everything: food, clothes, for everybody in the house." In her experience, it appears her husband would have one other partner, then take another once that relationship ended. Once the relationship is over, their financial responsibility is also over. This tradition is positive for the women with whom the husbands are having sexual relations, but can lead to the financial and material neglect of their original partners and children.

On a different note, Kiza mentioned an interesting and noteworthy issue related to the neglect of a partner's health. Kiza explained that after she learned that her husband was HIV+, she seriously questioned whether he knew his status prior to marrying her, but never told her. She related the following:

> *Kiza:* I mean to tell you the truth, I don't know if he had it before but he didn't tell me. Because, you know, African men, they don't act like…they will not tell you the truth concerning those kind of things. And I just accepted it and I said, 'Well, we are already married. We both have it so…'

Later in the discussion, we came back to this issue about her own husband and Kiza continued that the was at least aware that he was at-risk for contracting HIV:

> He never (pause)…he never said anything about that. You know? But, to me, I think, I think, he knew. That's just my thinking. But he never did say well… it could have been true. He didn't know because they didn't run any tests. But he knows he'd been having relationships without protecting himself. So, that

shouldn't be a surprise to him because if you don't protect yourself, that'll happen.

Unfortunately, Kiza doesn't believe her experience is unique. She explained how this situation can happen to women:

Kiza: But most of the women, they're sick and they don't know because their husband, even if they find out, they are not gonna tell them. And some of them, they're so mean. They will go and get treatment and don't tell the wife.

Joy: Their husbands?

Kiza: Their husbands, yes.

Joy: And do you think that's because of the stigma? Why don't they tell their wives? What are they afraid of?

Kiza: Well, they think if they tell their wife, you know…most of them are not at that level of understanding the situation. They are just afraid of their reaction. Some of them, they're just being mean because you know…well. And then, most women, they just look at it, 'Well, you get married for better and worse. So, it already happened. What can you do?!' Some of them, they know, but they won't tell anybody because it is taboo! You are not going to just go around and tell somebody about HIV. No!

“Do I just not exist?”: Emotional Neglect

For many of the women, it appears as though it was easier to have their physical needs met by their husband or intimate partner, than their emotional needs. Mary explained that although her husband would respond to her requests in terms of material needs for her and her children, he was less responsive to her emotional needs. For example, he had concurrent sexual partners outside of marriage and would often leave her and her children from Friday night to Sunday night or Monday morning, to be with his other partners. Mary knew about these partners though they didn’t speak openly about it. Sometimes they would call her home asking to speak to their “husband”. Occasionally, he would lie about these women but, in general, he didn’t make any excuses or apologize for his behavior. Mary thought it was normal because many other men in her community engaged in the same behavior. In fact, in her opinion, only one or two men out of 100 did not have concurrent partners. She stated that regardless of this behavior, her husband was not physically, verbally or sexually abusive. Instead, it appears he was emotionally neglectful. She declared: “He don’t care about affection” and continued in more detail:

> …my husband, he wasn’t the person to hurt somebody with words. Like when he would go outside on Friday and come back on Sunday, he looked like he was a little bit shamed… sometimes. He feel a little sorry, but not really sorry. At that moment, everything I ask him, he give me.

Liz had a similar experience with her American-born husband leaving their home to go be with other women. A woman would bring him back to his home in her car. He

would claim that his car had broken down, quickly pack up some clothes and leave again with the woman, saying he would be back when his car was repaired. This happened a number of times, but Liz thought this was normal behavior because of what she had observed growing up. Then one day she returned home after an errand and found a strange woman in her bathroom. She was in there for a long time and wouldn't come out. After threatening to call the police, the woman finally came out and Liz found condoms and blood in the trash can. She demanded to know what was going on but, she explained that: "(Her husband) didn't want to say nothing. He said he had nothing to explain to me. I was just like, 'Oh well.' I didn't make a big deal. I was mad and I forgave him after some time."

One of the women provided the following example of emotional neglect that she experienced after being treated for cancer and continuing to go to the hospital to ensure she was still in remission:

> *Participant (deidentified):* …Like I go to the hospital and my husband don't ask me, 'What did they say?' It's just like, 'You're back. Ok.' Don't ask: What did the doctor say? How are you feeling? So…and then maybe as soon as you walk in, 'Oh, what time are we gonna eat?' So, you feel like there is no consideration. There's no love. Do I just not exist? Yeah, things like that.
>
> *Joy:* Can you tell me more about this kind of 'Do I just not exist'? When do you feel that or how does that feel? ...Is it mostly because of you and your relationship or is it also because when you have problems or issues that come up, that you can't talk to other people about them?

Participant: Well, it's just like, I mean, usually, I'm not gonna go to… I like to deal with my problem myself. But when you address it, the only person that I can address the issue to is my husband. But he's just gonna make a big argument out of it and sometimes you just, you just decide not to talk about it. Because it's just gonna create this argument and, I mean… I'm talking about, especially my husband, he will be like mad at you, not talking to you for days! And it's just like, when it happens, you just don't want to talk about it because you don't want to be uncomfortable for days with someone just not saying anything to you.

Research Question 3: How do HIV+ African immigrant women describe their sexual decision-making?

In describing their sexual decision-making, the majority of the women in this study highlighted the lack of mutual decision-making and discussion with their partners. These women described knowing their husbands were having concurrent partners and not being able to stop the behavior due to established relationship norms. Furthermore, in addition to facing obstacles to saying, 'No' to sex, these women also faced barriers in being able to ask their husbands to use condoms, including lack of information about condoms. However, interestingly, the women suggested that it may be easier to assert their sexual right, such as asking for condoms use, with more casual partners. This would suggest that in these cases, married women may actually be at a higher risk for contracting HIV. Although most of these women were aware of HIV, in general, they did not have a full understanding of factors that put them at risk for contracting the virus. The

majority of the women also conveyed not actively engaging in family planning. These narratives were countered by the experiences of Michelle and Marcia, the youngest women in the same and the only two who did not contract HIV from sexual intercourse. These two women experienced great self-efficacy in terms of sexual decision-making. Gratefully, after her struggle with overcoming the effects of sexual and physical violence, Liz also experienced personal power in terms of her ability to engage in sexual decision-making with a new intimate partner with whom she can talk openly and candidly about sex.

"No, you cannot talk about sex.": No Discussion about Sex

In the women's stories, it is apparent that sex is not something that is readily and easily discussed between intimate partners. Ironically, there is also a common misconception that women who refuse sex, ask to use condoms or talk about sex must be having multiple partners. A discussion with Mary on this topic followed as such:

> *Mary:* … for sex (pause), I didn't know how to tell my husband that I need sex. Only him can start sex.
>
> *Joy:* So, he's the only one that starts that?
>
> *Mary:* Yeah, only one. If he say one month, it's okay. If one week no sex; one month, only him. Yeah. Sometimes (pause) it is something like when you marry, you never know how to tell your husband 'Let's do sex'. And after a year, you start to ask him. He can think maybe you are doing…you found someone outside.
>
> *Joy:* Oh, so if you ask him for sex, he might think you are with someone else?
>
> *Mary:* Yes.

Joy: Because only a woman who did that would be able to talk about it, or?

Mary: Because when you marry, for you it is only men who can ask for sex. No, you cannot talk about sex. No.

Counter Narrative

Both of the women who contracted HIV as children married HIV- men. They both engage extensively in communication with their partners about issues related to their reproductive and sexual health. Marcia described making decisions equally with her husband in terms of using condoms, deciding to get married, and deciding how many children to have children and how to conceive them. Michelle also discussed these issues in partnership with her husband, though she described having a bit more power than her husband in terms of sexual decision-making because of her fears around him contracting HIV and, thus, her repeated efforts to convince him to be tested on a regular basis.

"Even if you know, what are you gonna do?": Multiple and Concurrent Partners

As discussed earlier, it is widely believed and largely accepted that men from their home communities will have multiple, and even concurrent partners. Multiple partners are consecutive; meaning one after the other. However, concurrent partners are in sexual relationships with the men at the same time as the main partner. This puts women at enhanced risk for contracting HIV. Some of these sexual relationships are formalized through marriages, some are acknowledged by the men taking on financial responsibility for the women and some are casual. Regardless of the exact nature of the relationship, this is a behavior that has been normalized in the community and, by extension, the

women. For example, Liz explained her view of her partner having concurrent partners. She said: “A lot of African men, it’s hard for them to be with one woman. You feel like they have to do that.” Kiza agreed that most men have concurrent partners. She clarified that they are concurrent partners, not just multiple partners. She explained: “They might be married, but at the same time they have, you know, a mistress on the side.” She added that it was her experience, as well as the experience of others that she’s observed. With regard to whether the wife or partner know about these other sexual partners, Kiza stated:

> Sometimes they suspect, especially the wives. Even if you know, what are you gonna do? There is only one thing that you’re gonna do. It’s divorce….You don’t just divorce just because you are suspecting something or because he’s messing around with somebody else!

Thus, we see the conundrum these women face: if they realize their partner is having other sexual partners, they are under pressure to stay married and maintain his sexual interest. This pressure to maintain their relationship puts their sexual health at risk. Kiza, herself, made the connection between men having concurrent partners and the spread of HIV. She explained the connection as follows: “You know, people they contract the disease because the men have different, you know, mistresses or wives and, you know, things like that. And most of the women, they are just victim of things they cannot control.”

Counter Narrative

Although both Michelle and Marcia are aware of the common practice of men having multiple partners and even concurrent sexual partners, this issue did not come up with either of them in terms of their intimate relationships. Thus, perhaps it can be assumed that this has not been an issue in their relationships, nor do they expect it to develop.

"You cannot ask your husband!": Barriers to Using Condoms

All of the women who contracted HIV from sexual relations stated that it is not possible to ask husbands to use a condom. Furthermore, it also appeared that their male partners had more information on condoms. Interestingly, it appears that in these women's experience, it is easier to ask a man to use a condom if it is a more casual sexual relationship. Michelle and Marcia have had very different experiences with condom negotiation than the other women in the study. They both married HIV- men and talk with them extensively about condom use, demanding that they use condoms consistently in order to maintain their husbands' negative status. They also stated that it is not easy to always use condoms consistently so both the husbands and the wives support each other in maintaining this commitment.

In terms of knowledge regarding condoms, Brenda Lynn and Mary did not know about condoms while living in their home countries and, therefore, couldn't ask their partners to use them. Mary conveyed that her husband most likely condoms with more casual partners. She remembered: "One day I remember I found, now I understand it was a condom. I asked him, 'What is it?' 'It's something…'. He explained to me a lie, I don't

remember. Only when I came to America I found out it was." Presumably, information about condom use is more widely known these days, however, it may be possible that there are pockets of communities where this knowledge is not readily available, let alone access to condoms, which Kiza states are not easily accessible.

When asked whether it is possible for women to ask their husbands to use condoms, Brenda related: "Some men don't even like to hear about it, say, 'You can't tell me what to do.' Some will tell you, 'You are my wife and you have to hear from me, I can't hear from you." Kiza agreed that this male-dominated view is common. When I asked Kiza if it was possible for women to ask their husbands to use condoms, the following dialogue emerged:

Kiza: You cannot ask your husband! I mean birth control…you know, they kind of understand.

Joy: Like pills or?

Kiza: Yeah, but if you're gonna ask your husband to use a condom, it's not gonna work! I mean (laughter), that is a 'No, no, no!'

Joy: Have you ever had experience with that?

Kiza: Yeah, because your husband cannot use a condom with his wife...I mean, 'I cannot use a condom with my wife' *(imitating a man).*

Joy: So, did you have any experience where you asked your partner to use a condom and they refused or did you know not to even ask?

Kiza: You wouldn't even…even if when you ask, he would tell you, "What is wrong with you?'…. As long as you are the wife, you cannot say that. Maybe boyfriend and girlfriend, they might, but not husband and wife.

This is an interesting concept that it may be easier to ask for condoms from non-marital, or casual sexual partners. This situation puts married women at an increased risk. When asked whether she could ask non-marital sexual partners to use a condom in the past, Kiza stated: "Oh, yeah! When you're dating, you have the freedom because you are not married." Marcia and Brenda Lynn agreed. Brenda Lyn stated that it is easier for couples to use condoms if they are not married. She believed that some unmarried couples used condoms and some didn't. She even stated that some married men who sleep with casual partners may use condoms. This would correspond to Mary's story about her husband having condoms, but not using them with her.

Brenda Lynn added that: "Most men in Africa when they even hear about condoms, when you use a condom, when they have sex with her, they will tell you that you they don't need it." When imagining if she had known about condoms when she was married and whether she could have asked her husband to use them, she said: "I don't know. Maybe he would fight me if I have to to use a condom. He would accuse me I was sleeping with other men." Kiza also commented on situations in which a woman asks a male sex partner to use a condom or get tested, they may accuse the women of cheating. She stated:

> It's just a manipulation things. It's so they twist it around, then, you know blame it on you…but they know. People they know. Even men they know! Even women, they know! But it's just the manipulation things that they would use…. So they just manipulate the situation that way. It's the manipulation. It's intimidation. You know, so, it's like they just want to have it their way.

Counter Narrative

Marcia married a man who is HIV-. They are both committed to doing everything in their power to help him maintain his current status. They both help each other reach that goal. She revealed: "Sometimes we fail, I can't tell if it's my fault or his, we have to do our best, but it's not really easy." Michelle and her husband go through a similar process. Marcia explained the following in terms of the sexual decision-making process she goes through with her husband:

> *Marcia:* The decision was about marriage because my husband was negative. So, I thought how can we get married if he is negative and I am positive? Because I thought he would want to have kids. Me too. I said we have to: he can look for someone negative and I can look for someone positive. The decision was how to do sex using condoms. It was a big deal because, how can I explain ...? When you are together, sometimes you can be… you can use a condom, and it can be inconvenient, not comfortable. But we have to stay firm on the decision, that is what's really difficult to do.

Joy: So, that negotiation about whether to use them, so it sounds like you made a decision to use them, and then you have to kind of help each other to continue to use them, to continue to stay with that decision?

Marcia: Yes

Joy: And how did you make that: is that together, is that something that's more important to you, is it something that you decided together?

Marcia: At the first time it was my decision, but my husband has to understand too that it's very important to be safe, to use condoms. When it's my weakness, he remembers, the same to him. I have to remember him, to use a condom.

"I didn't even think that he could go and get it somewhere and give it to me.": Knowledge of HIV and Testing

Many of the women also explained that they did not have a full understanding of HIV, especially their risk factors for contracting the disease. Because of this lack of knowledge, asking their partner to be tested wasn't a realistic option for them. Brenda Lynn says she knew about HIV when she lived in her home country but wasn't aware she had it. She explained:

> They tell us that some people use a condom, but I had never seen it before. I don't know how they even used it. But I knew about HIV because a lot of people were dying. They were sick and dying from HIV. So I know of HIV."

Brenda Lynn also knew that her husband was sleeping with other women and that HIV was spread through sexual contact, but didn't realize that could put her at risk for contracting the virus. She stated: "That did not even come into my head. I didn't even think that he could go and get it somewhere and give it to me."

Mary also said that she had heard of HIV because one of her cousins had died of AIDS, but she didn't know she was at-risk. One of the reasons she didn't realize she was at-risk was because she put so much faith in her husband's intelligence. She didn't feel like he was the kind of person that would contract the virus. She explained:

> *Mary:* Yes, I heard about HIV. I heard about it because I lost one of my cousins with it before '90. Yeah. But, for me, my husband, he was very smart. I don't think he can get it.
>
> *Joy:* You thought he was smart, he wouldn't put himself at risk?
>
> *Mary:* I don't know, but for me, I was just thinking, he cannot get that. Because for it, it was like a dirty person. Yeah….
>
> *Joy:* Just so I understand, so you knew about HIV and you knew you could get it from sex, but you didn't feel like your husband could get it because he was clean and smart.
>
> *Mary:* Yeah, for me, I know that if somebody have HIV, he have red… you know, he have skin (motioning skin problems/lesions), so my husband cannot go with people.
>
> *Joy:* OK, so you thought he could see it and he would avoid that.

Mary: Yeah, I didn't know it took too many time, too many days, years before you see it.

In terms of testing, it also appeared that there were a number of barriers, similar to those related to condom use. Kiza stated that: "You can't even ask, 'Before we start this relationship, can we go on and do the test?' No, can't do that." She later explained that people are so afraid to get tested that they are afraid to go to the hospital, thinking that they will automatically be tested without being asked to provide their consent:

….Some people don't even know where to go (to be tested) because they don't want to talk about it. They won't talk about it! They won't get tested! Even if when you see them, unless they think when you go to the hospital they do the HIV test, which they don't because you're gonna have to give them permission.

Similar to Marcia, Michelle engaged openly in sexual decision-making with her husband, actually taking the lead in a number of issues. Her active participation in sexual decision-making is mostly inspired by her desire to maintain his negative HIV status. For Michelle, working to ensure her husband stays negative is one way she expresses her love and care for him. She explained:

Michelle: OK, 'cause I am positive, he's negative, I'm very strict. 'Cause I feel like just 'cause we are married doesn't mean it's okay for you to be…positive. It doesn't matter how long we've been together or how long we will be together, I feel like that part right there is important to me. So, I always make sure that he is

protected. That's one thing. And I always make sure that he gets tested. I know he, literally, he hates it.

Joy: Hates being tested, or hates what?

Michelle: Yeah. He hates being tested. 'Cause he says he feels like he's...belittling me or making me feel like… (pause). I guess he doesn't want me to feel guilty if he ever was positive. Which I know I would. I know that because I'm the one who's positive. So, if he gets it from somewhere, he's gonna get it from me. So, he hates being tested because of that. He says he doesn't mind being positive. But he feels it would affect me emotionally.

Joy: So, it sounds like he would almost rather not know.

Michelle: Yeah, but I would want him to know because not knowing is…that's bad. You are supposed to know (sigh). You need to know if you have it. You should start taking care of yourself. And he's always like, 'I don't care if I have it because we are together.' And I am always the one saying, 'No, it's not like that. I'm gonna show you that I love you by keeping you negative.' That's my goal. So, (sigh) it's also about time for him to get tested (laughter).

Joy: How often does he get tested?

Michelle: Every 3 months. We usually come here or (another clinic). They have like a thing where... they have free testing. So, I make sure that he gets tested.

Joy: And he goes reluctantly?

Michelle: Yeah, he really does! So, I have to keep reminding him and reminding him and then he will just get annoyed and just do it. But I have to make sure that

he's negative. 'Cause I know that if he was...ok, I know that if I became selfish, or if I just didn't care and then he becomes positive one way or another, I'm gonna beat myself up so bad! I already know that. So, I would rather prevent that. 'Cause I don't…I don't want to feel responsible or feel like, 'Oh gosh! I ruined his life.' Even though I already know how to live with the disease, it took me a while to be able to live with it…. So, yeah. I make sure (laughter)!

Joy: So, you make sure that you have safe sex, that you use condoms and things like that and that he gets tested.

Michelle: Every 3 months.

Joy: And so, it sounds like there is a little bit of disagreement on that, but he…follows your lead on that.

Michelle: Yeah, 'cause I expressed my feelings. I'm very opinionated I guess. I expressed my feelings about it. You know, I didn't choose to have this. But because I have it, I have to deal with it. He like, he, I don't want to say he has a decision too but, if he had it, he would know that, 'Ok, I got it from this place because of this.' And it won't be a surprise, but it would still be a shock. So, I wouldn't want that. I don't know, I just, I already know myself emotionally. I wouldn't be able to deal with it…. So, I feel like that's …a lot of pressure. But it's a decision that we made to be together… 'Cause that's one of the things that I make sure that I stressed before we got together.

Joy: So, before you were married, when you first started dating, you had this conversation to decide whether or not to be together and you made the decision and he made the decision and you came together.

"They don't believe in stuff like that back home.": Family Planning

Few of the women mentioned actively planning the size of their families or trying to control their fertility. When asked whether she and her partner planned her pregnancies, she stated: **"**You don't plan nothing!! You just marry for kids, for making kids! (laughter)." In terms of family planning, Kiza said that it is possible to talk to partners about using the pill. In contrast, condoms may be used for birth control in some situations, but it is seldom done. When asked about birth control and condoms, Liz stated:

> They don't believe in stuff like that back home. Maybe now, I don't know. But they don't believe in that. Birth control is like they tell you tried to kill some children or something. I never use birth control or condoms when I was back home. I know about them, I use them here, because I had to learn more about that.

Brenda Lynn described a situation in which she used birth control in order to prevent future pregnancies, but felt she had to do so secretly, so as to not upset her husband. She decided she didn't want to have sex with her husband because she didn't want to have any more children because he refused to financially support the children they already had. This was not something she could discuss with him. There was a period

after her last child during which she was buying birth control (the pill) from a pharmacy for two years without him knowing. At the time, she didn't know about condoms. Until that point, she and her husband had wanted to have a kid every two years. When she told him she didn't want any more children, they fought. So she decided to take birth control secretly. She said many other women in her community also take birth control secretly because there was pressure to continue to have more children. When asked why she kept it secret she said: "I think I could have told him, maybe he could hit me or harm me, and say that you don't want to have another kid. I didn't want him to know."

Counter Narrative

In contrast to the other women, Marcia and Michelle have engaged in detailed planning in terms of starting their families. Marcia provided extensive information on how she and her husband engage in family planning. Michelle also does. Marcia gave an example in which she and her husband came to an agreement on how many children to have. At the beginning of their relationship, she wanted three children and he wanted two. In the end they decided to have two children due to their move to the US and new conditions. Marcia stated that from the outside, it might look like her husband made the decision, but it was actually the result of examining the new conditions together and making a compromise. Marcia also provided an example in which they decided to go to the doctors to discuss artificial insemination in order to pursue their dream of having children while protecting her husband's negative HIV status. She stated: "It's really not comfortable, it reminds you you are not like other people (meaning she is HIV+)"

Nonetheless, she and her husband chose to undergo the procedure because of the importance of maintaining her husband's status.

Michelle also participates equally in sexual decision-making with her husband. She experienced her budding relationship and romance as a happy surprise because she worried about finding a life partner after learning of her status. She explained: "…there was one time in my life I told myself, 'Ok, you know what…I'm never gonna get married because no one is gonna want me because of this disease. I'm never gonna have children. I'll probably just be alone." However, this was not the case. Her husband was very accepting of her status and they developed a plan, involving condom use and HIV testing, to manage his risk. When asked if she and her husband have discussed having children, Michelle's response didn't even mention her HIV status. This exhibits the fact that her status is only a small part of their decision. They have many dreams and goals that will likely play a larger role in their decision. Michelle explained:

> No, we have. We have. Like, I'm very the way I was raised up....I want to finish, not finish school, because I know that's gonna take a while. But, I want to be at a place where I know that if I have a kid, I will take care of that kid. Like financially, I wouldn't be struggling. And that's how I've always been. And we've talked about having kids actually. Mom wants me to wait until I'm (older)…. I have this picture in my head of this family that I want. I know people don't get what they want. But I want to get close to that. And I just want to be, not safe, but sure that, ok, nothing bad will happen. Like, we'll be set. No problems. I mean life is crazy. But I at least want to get close to that.

“Now I know about it and I don't want to give it to somebody else.”: Sex and Being Positive

The women have taken a variety of approaches to taking care of their reproductive and sexual health, as well as that of their partners’, since being diagnosed as HIV+. Mary has chosen not to be in a relationship or to have sex. In her whole life, she has only been with her husband. Thus, it is possible she would have made this choice even if she wasn’t HIV+. Brenda Lynn also doesn’t have a sexual partner or express any immediate interest in finding a partner. In discussing how things might be different with potential future partners, she stated: “I think it would be different because maybe the person, like here maybe we would use a condom. I think that's the only thing, to have that person not get infected with the disease…. Now I know about it and I don't want to give it to somebody else.” She added that she wouldn’t reveal her status to a future partner, but she would only have sex with a condom. If he refused to use a condom, she would refuse to have sex. Interestingly, it seems that for some of the women, it is easier to demand that their partner uses a condom now that they know their HIV status. It seems as though, in a way, it is easier for them to insist on safe sex in order to protect someone else’s health, than their own. My conversation with Brenda Lynn continued as such:

> *Joy:* And do you feel confident, if you had a partner, you could ask him to use it?
>
> *Brenda Lynn:* Yes, now. And if he said, ‘No’, I would say, ‘No’. I will not tell him that I'm sick. I will say, ‘If you don't want to use a condom, I will not have sex with you.’ I would tell him, ‘No’.
>
> *Joy:* What has changed? What makes you be able to ask for that now?

Brenda Lynn: Because I know that I'm sick. I don't want somebody else to have that; the same problem.

Joy: Has your relationship with men changed? Like we talked about before, maybe if you were dating you could ask if they would use a condom, but if you're married it's very difficult to ask someone to use a condom. Has that changed for you here in the US, or is it that you know you are positive?

Brenda Lynn: It's still the same because now I am alone. And I don't have any friends here in the US. Except if I had a friend here now it would change because I would tell the person, 'We have to use a condom. There are a lot of people out there who are sick. You don't know, so we have to use a condom.'

Joy: It sounds like you want to use a condom to protect the person but you would try not to tell them.

Brenda Lynn: No, I would not tell the person.

Joy: Because the information could get back?

Brenda Lynn: Yes.

Joy: So you would be careful, but you would still keep it secret?

Brenda Lynn: Yes, I will not allow myself. I will not go to bed with you without a condom. If you don't want to listen to me, I will tell you, 'No'.

Both Kiza and Lisa have current partners who are HIV+. Although Liz doesn't have to worry about her partner contracting HIV, she still takes the opportunity to speak

openly with him about sex and enjoys her ability to make her own decisions about her reproductive and sexual health.

Research Question 4: Do HIV+ African immigrant women talk about contextual factors, such as poverty and migration, when they discuss their HIV status?

The stories of these HIV+ women shed light on the contextual factors that influenced their risk for contracting HIV. Issues of migration did not surface in the women's narratives as extensively as I was expecting. I had anticipated that the sample might largely consist of refugees and thus that migration would significantly influence their risk levels, especially for those who lived in countries of temporary settlement in refugee camps. However, the sample did not consist of refugees, so this was not the case. Nonetheless, the women did discuss financial issues affecting their risk levels. Interestingly, in terms of risk factors, the women did not speak directly about the role of poverty, however, they did speak rather extensively about who in the family controls the money and the impact that can have on their lives. Two of the women had husbands who did not consistently contribute to the financial well-being of their families, and for one of the women in particular, this put her at risk as the situation forced her to engage in survival sex in order to provide for her children. Related to this issue is financial dependence. In general, the women felt that this was less of an issue for them and more of an issue for their female family and community members in their home countries. They felt that the constrained employment and income generating opportunities these women had put pressure on them to be married and stay married regardless of whether the relationship was a healthy one. Finally, the women expressed gratitude for the

opportunities they received in the United States, particularly in terms of accessing HIV-related medication and treatment.

“You have the money why can't you just help us?!”: Who Controls Money

In the stories of these women, it seemed less important how much money they had and more important who controlled the money. Brenda Lynn showed the importance of this issue because although she and her husband probably had enough income to care for their family’s needs, his lack of financial support forced her to eventually leave him and engage in survival sex in order to support her family. Brenda Lynn explained that during their marriage, he didn’t want to share his income with his family, so she would have to rely on friends in the community to intervene on her behalf and make him share his money:

> And that's what made me separate with my husband. Before I came here (United States), he didn't like to take care of the kids’ going to school. I was doing everything. And money; he could not support me or pay the fees. I alone would be doing this or doing that; all he did was drink.

Brenda Lynn explained the lengths to which she would go to get money to feed her children. She stated:

> I used to fight with him at times because sometimes he would use to go when he had his money like that. He would go and stay in the bar drinking with other women. I would be there in the house with the kids and no food. I would do everything by myself. So I would start fighting. That was another problem.

She continued:

> Sometimes he would get his salary, I would need money to buy food and he wouldn't give it to me. I needed to pay the house rent, he would not do that. So, I would start fighting so I could get money from him to buy books for the kids. Nothing until I'd fight and quarrel with him. He would not until he would remove money from his pocket and give it to me.

However, toward the end of their marriage, even this external pressure did not work and she was eventually forced to become estranged from her husband and engage in survival sex in order to have sufficient financial means to support her family. In her words:

> At first I was just persevering because when he did that, when I would call somebody and tell the person or tell him, 'No, you have the money why can't you just help us?!', then he would give me the money. At the end, he didn't want to give me the money anymore, even if another person comes. Then he would say, 'It was my money and I will not give it.' That's why, if so I'm not staying anymore.

No matter how much Brenda Lynn and her children suffered because of this situation, she indicated that this problem was not unique to her family, stating: "Most people have kids, but they don't take care of their kids. Just the women take care of the kids….(The men) just want their money. It's for them."

Liz married an American –born citizen who became physically abusive and addicted to drugs. He physically neglected his family; not sharing his own paycheck, while also wanting Liz's income from the side jobs she was doing. Liz described the scenario as follows:

> When he got paid from work he goes and spends his money. Then, you know, I am going to get paid anyway. He wants the money when they give me the money. And he wants that money so he can keep it for me. I am like, 'I can keep the money and I can buy what I want to buy with the money.' That was an issue. One time he threatened me. He had a bottle and he threw it on the mirror and broke (it), but the (children) were at school, because I said, 'No' to giving him some money. But you know after all the arguments, I end up giving it to him. Every time (my employer) gave me the money, I saved a little bit. I put it in a piggy bank. I don't know how he found out about the piggy bank and he started getting money from there without me knowing, until one day he just emptied my piggy bank and took it. It was all the money that was in there. He said he didn't know, maybe somebody else got it, but I know he's the one that got it.

Mary's case was less severe. She had a husband she considered fair and even generous. Nonetheless, her husband definitely had the main control over the money, although he made sure her material needs were met. Mary described control over money as follows:

> The money, it look like it is for us. It is for him, but it look like for us. Even he tell me, 'Go buy this, go buy this.' When I buy, I come and explain to him. But he was a good person... I tell him and he give me money when I need something.

Marcia and her husband, who make joint decisions, offer a counter narrative. She is currently a stay-at-home mom. Even though her husband is earning all of the family's income at this time, they come together to plan how to budget and spend the income. This is different from her family of origin in which both her parents worked and paid for their own expenses separately. Thus, we see that even though her parents did not cooperate as effectively as Marcia and her husband, her mother was able to exercise decision-making in this area and this may have influenced Marcia to make sure she has a say in her family's finances. In Michelle's case, she takes the lead in her marriage when it comes to paying bills, budgeting and engaging in financial planning. She would welcome her husband's input, but it seems as though they both feel she is better suited for this work; work that she observed her mother doing when she was growing up. Thus, perhaps it is not a coincidence that we see that the women who had to fight for access to their family's financial support were also the women who contracted HIV through heterosexual relations with their husbands, as opposed to the women who were infected as children and engage in equal decision-making with their husbands.

"Before he comes to help you, you must have sex with him.": Survival Sex

Brenda Lynn shared her experience of physical neglect, in which her husband refused to share his income with his family for their support. Instead, he chose to use it

for his pleasure; mainly to purchase alcohol. She stated that this behavior was not unusual in her community. After she eventually left her husband, she needed to find a way to supplement his missing earnings. Thus, after becoming estranged from her husband, she began engaging in survival sex with local men. She stated that this was a fairly common practice in her community; something even married women would engage in secretly in order to be able to financially support their children. During our conversation, she described the dynamics of survival sex as follows:

> *Joy:* If you are not married and you leave your husband or if you get divorced, then you are more dependent; you need more financial support. Tell me about that pressure. Men will offer to help you?
>
> *Brenda Lynn:* Yes.
>
> *Joy:* How will that happen?
>
> *Brenda Lynn:* Before he comes to help you, you must have sex with him.
>
> *Joy:* Does he tell you that or do you know it?
>
> *Brenda Lynn:* Yes, he wants sex with you before he helps you. If you don't, he won't help you.
>
> *Joy:* So, he will say, 'I want to help give you some money'?
>
> *Brenda Lynn:* Yes, 'I want to give you some money, but we must do this before I give you some.'
>
> *Joy:* Is this someone that you're dating? Is this like a boyfriend or someone you have a relationship with or is this one time?
>
> *Brenda Lynn:* They can just come and give you the money and go or another

person can come. You can have another person. That's how it happens. Not one person.

Brenda Lynn continued by clarifying that these are not men with whom she wanted a relationship. The purpose was just to get extra money for her family. From Brenda Lynn's description, it is unusual for a woman to be living by herself, so when men find a woman in this situation, they often come to her and offer their financial help in exchange for sex. Brenda Lynn explained that she would have much preferred to stay with her husband than to engage in survival sex, but wasn't able to due to his sexually violent behavior and physical neglect of his family's needs. Unfortunately, Brenda Lynn revealed that she still didn't know about condoms at the time and none of the men mentioned using condoms to her. Thus, in effect, her husband's neglect of the family's financial needs led her to engage in a high risk behavior that may have even been the source of her HIV infection.

Since living in the United States and having her friend take care of her expenses, Brenda Lynn has not had any sexual partners, nor does she report a need to engage in survival sex. So, this strategy was appears to have been a time limited effort to support her family. Additionally, Brenda Lynn explained that young unmarried women also often engage in this behavior. Young unmarried women who stay with their families and are financially supported by them do not need to engage in survival sex. However, those who are unmarried with children have more pressure to do so. Brenda Lynn clarified the situations that can lead to survival sex as follows:

Joy: I am trying to make sure I understand when this happens. Does this also happened for young girls who have, like when you were young girl you had a child (before marriage) and your parents took care of you, but if they didn't take care of you that could've happened?

Brenda Lynn: Yes, that's how it happens.

Joy: So, if you're young and you have children and you're not married…

Brenda Lynn: (finished sentence) You go out there.

Joy: Or, if you get divorced, or even if you're married and your husband doesn't take care of you…

Brenda Lynn: You go out. If your husband doesn't take care, you do.

Joy: So, if you're a young girl and you haven't married yet, and you don't have children, will you still need to?

Brenda Lynn: If you still need help (pause).

Joy: So, it's really only if you have kids usually that the women do that for more help.

Brenda Lynn: Yes, they do that for help.

Financial Dependence

The women interviewed for this study shared their experiences living in their home countries, as well as living here in the United States. Virtually all of the women expressed concern for female family and community members still living in their countries of origin because they felt limited educational and economic opportunities put

the women at-risk for contracting HIV. Therefore, they were concerned for both their material needs, as well as their emotional needs. The women believed that those women's lives were much harder and that factors, such as financial dependence on men, as well as norms in which men can dominate women, put them at significant risk.

"Sometimes many days no food": Material Concerns

When discussing this issue, Kiza stated that she believed the women back home need help but was unclear what resources would be available to them. Depending on which country the women were from, some of these concerns come from an unstable, dangerous and difficult situation brought on by political conflicts and instability. Mary stated that violence against women is increased during war and the situation continues to this day in which people can come to your house and rape you. She also described her concern for her (female relative) still living in her home country based on the scarcity of basic goods, including food: "I don't know how she can get over here. It's very painful. When we talk on the phone, she cries. I cry. I want her to be close to me, but sometimes many days no food." Thus, we see conflict can put women at-risk for experiencing violent victimization. Furthermore, the lack of basic goods, especially including food, can put women at-risk of becoming financially dependent on men or engaging in survival sex; both of which would increase her risk for contracting HIV.

"A lot of different things that women there are thinking that's okay. It's not okay.": Emotional Concerns

Liz's concern for women back home was less about their material well-being and more about how they are respected in their relationships and whether they are abused. Of

her concern for women back home, Liz stated: “I wish I could do something; go back to (home country) one day and teach some women about self discipline, self esteem, just a lot of different things that women there are thinking that’s okay. It’s not okay.” Liz is keenly aware that women in abusive relationships are at higher risk for contracting HIV because they may not be able to say, ‘No’ to sex with high risk partners, or they may suffer from sexual violence. But Liz feels hopeful for other African women: “Even the other women, there will come a time when they will sit down and be truthful with themselves and love themselves more and feel like it’s okay to talk about stuff.”

“But even if you tell them while they are still depending on a man, it’s not gonna work.”: Risk for HIV

When questioned whether financial dependency of the women on men increases their risk for contracting HIV, Kiza stated that she did not feel this was true for African immigrant women living in the United States because, in general, they work and often even earn an income that is commensurate to their husband’s. This also led us to a discussion that for African women living in the United States, the status of being married may be even more important than the financial aspect since many of them can support their own needs. She also argued that men treat women who bring in an income better.

Unfortunately, she said that many of the women back home do not have jobs. Thus, Kiza felt the risk for contracting HIV for women back home could be lowered if they were able to experience financial independence. She related that in the United States, African immigrant women have pressure to marry due to the status associated with marriage. For African women living in their home countries, she believes they face

pressure to be married due to the social status, as well as the financial stability. This puts the women at enhanced risk of contracting HIV because it limits their options and makes it more likely that they will tolerate negative behaviors, such as being disrespecting or having husbands with multiple partners. She explained:

> *Kiza:* Well, I think most of the women (in her home country), even though they really want to be married, but right now even if they can have some financial stability, I think most of them now, they would react different towards men. But it's even if they want to, but they don't have any other resources. I mean, I mean, it's something that needs to be created for them to be busy working or making some money. So, that way they are going to have the courage to say, 'No'. The courage to do certain things. But even if you tell them while they are still depending on a man, it's not gonna work. 'So, you're telling me to leave this man if he isn't treating me right? But how am I going to survive out there?' (imitating a conversation). And most of them, they are not really educated and it's not like over here; you have work, like a factory job. See most of them they work, they repair cell phones, they do this, but you know, they have a little (income)…Some of them, you can tell they start, you know, kind of because they know they can go to work. They can make a little money, they act a little bit different.
>
> *Joy:* Like they stand up for themselves a little bit more?
>
> *Kiza:* Yes….Even though they want to be married, but some of them, they're at the point where they are just tired. Like they just don't; even if they want to get out, they can't get out. Even if they want to tell the man to go… But you know

men when they know that you bring something, you have some type of education, they would treat you a little bit different than the one who doesn't have any other way of surviving.

Joy: So, there is still a lot of pressure on women here, but they are treated a bit differently because they are more financially independent?

Kiza: Yeah, they are bringing in something. You don't want to let her go. Because at least when she is upset about something, you are gonna try. They act much better over here than back home.

Joy: So, is the pressure to be married even stronger over there?

Kiza: Yes.

In addition, there are situations in which women marry older men for financial security. This can compound their risk. When asked why this occurs, Kiza explained:

For financial reasons because if you came from a poor family and you are not educated and you see this man is wealthy and everything else, even if they tell you that he's old and he's been married, you know, you're just gonna go. 'Cause you just want to be where you can be comfortable and be able to help your family.

"And every time, every week, one day, we gather together to pray for America.": Gratitude for Being in the United States

The women in this study expressed a deep gratitude for living in the United States; feeling that their material and emotional needs were better provided for and protected in the United States. This is related to their perception of contextual issues,

such as poverty and political instability, as well as lack of access to HIV-related medicines and treatment; all of which are mitigated by living in the United States. Thus, the women seemed to believe that had they not been able to come to the United States, their outcomes would have been much more negative, especially in terms of their health status. They believe the contextual factors they experience in the United States give women here an advantage in reducing their risks. If only these advantages could also be available to the women they care so much about back home.

Mary expressed a feeling that if she was in her home country, she may have already died from HIV. She said:

> Because people dying with that (AIDS). And I thank God every day. I pray for miracle. I pray. I tell my kids, 'Pray for America. Let God bring peace in this country.' Can you imagine, if I was in my country?! No school for my kids. But we are safe over here. Even work is hard, but we still live inside the apartment. We find good water to drink. And every time, every week, one day, we gather together to pray for America.

Michelle also expressed gratitude. She was very ill when she was first diagnosed with HIV and she feels that she came close to dying and that if she didn't live in the United States, she may not have survived. She described it as such:

> *Michelle:* Yeah, because to have a CD4 count of 1…that's like, I was this close (gesture) to having AIDS if the doctor hadn't done anything. And the way I look at it, if I never came here to America…(laughter)… I would not be here right now

(laughter). And, I don't know, it kind of shook me up a little when I thought about it. Because it is not like they knew I had, my parents knew I had it, but they just said, 'Oh, let's just go because mom is there. Let's just go to America!' So, I don't know. I guess things happen for a reason.

Joy: So, you feel like… maybe you wouldn't have been tested there, or maybe the medicine would have been less successful? Or, what do you think would have been different?

Michelle: First of all, I don't think people would have known what it is until it was too late; until it was full blown AIDS and there was nothing they could have done about it. And I feel like, because of stigma, people wouldn't have wanted to deal with you, as far as doctors and nurses and stuff like that. So, I feel like the health care, the medical thing, would not be there. Medication? I don't know how expensive medication is in Africa. I don't know. But I don't know…maybe I would get it, but it would probably be too late.

She stated that people often tell her she is very mature and sure of herself for her age. Her gratitude for her life in the United States, as well as her optimism for the opportunities that await her are evident in her response. When responding to those statements, she shares the following with people:

My answer is always, 'I almost lost my life several times before like (sigh)…' I don't know…. But I've had very close calls and I know you only live once. I learned that. I learned that. And I was in the hospital… when I had that fever, they

were like, 'We don't know if you are gonna make it.' That was scary! That was scary! I still remember that 'til this day. That was scary! 'Cause I don't know where you go up to die after death. I remember looking at my mom and she was like crying. She doesn't know what to do. And I am seeing all of these doctor's coming in and nurses and I am like, 'Oh my gosh!' That's all I remember, in my head, 'Oh my gosh, it's over!' Then I remember waking up like, 'Oh, okay, it's in the morning now.' And I remember all of that. That's why I feel like I'm not gonna waste my life trying to stand still. I believe in just doing things. Well…moving forward and just doing things. I want to experience everything.... (Husband) told … I give him hope or like that feeling that you can actually do anything that you put your mind to. I didn't know I could give people that feeling (laughter)!

Research Question 5: What do the stories of HIV+ African immigrant women teach us about HIV?

The narratives of HIV+ African immigrant women were key to understanding the varied and complex factors that put them at risk, as well as highlighting the fundamental dynamics increasing risk levels for all women. Their narratives revealed the intense, overwhelming and distinct stigma against HIV+ individuals in the African community abroad and in the United States. They also highlighted the intense pressure these women faced to keep their status silent. The silence surrounding their status was not the only silence these women faced. Their experiences of sexual violence were also often hidden. Some of the stigma the women feared and the silence they kept were due to the deep

connections these women maintained with their families and communities in their home country, as well as their fellow countrymen living in the United States. This connection often reinforced social pressures to maintain "feminine" modes of behavior, such as remaining quiet, demure and acquiescent. One of the places in which these connections were maintained was in their faith communities, specifically their churches. Their churches often served as sources of strength and community for the women, while also preserving cultural ties and expectations for the community as a whole.

The Power of Stigma

According to the case manager serving these women, the immense fear of exposure these women experience seemed to be greater than that which other populations experience. This is due, in large part, to the intense stigma against HIV+ individuals in their communities. It appears that their fears related to the stigma of HIV are due to the deep connection they have to their home communities; places in which the stigma against HIV seems, in general, to be different and perhaps more biting, than it is in the United States. Nonetheless, the stigma they face in their home countries is reflected in their community in the United States. Thus, the gossip that continues in the community of their countrymen here spurs on their fears that people back home will learn of their status. The women also expressed a fear that if their status is known that people will harass their children for having a mother who is HIV+. Another part of the stigma is due, in part, to the strength of the misinformation and myths in their communities of origin regarding the transmission of HIV. Thus, these women are afraid they will be avoided by loved ones and treated as "lepers" once their status is revealed.

"It's just gonna be the talk of the town, you know.": Fear of Gossip and Mocking

The women reported others mocking and laughing at people who were HIV+. In general, they seemed more concerned that people back in their home country would find out about their status. The women are very tied into communities of people from their home country living in the United States and they were afraid their fellow countrymen would pass the news along back home. Mary works with a number of people from her home country. It seems that gossip was a very real problem among group members. For example, Mary's coworkers asked her why she does not date anyone and have even made statements such as "She is strong because she don't have sex." It seemed that these discussions increased Mary's fear that, if revealed, they would gossip about her status.

Regarding this gossip and speculation, Kiza explained that even people who are educated about HIV push that knowledge aside to point fingers at one another. She stated: "Even the educated about it…they just kind of push that education away…. 'He is. She is (pretending to point).' It's just gonna be the talk of the town, you know. So, you just don't want that." She also added:

> I can talk to the people over here (AIDS organization). But I cannot talk to the people in my community. I mean, you don't even want them to see you over here! Because then it's gonna be the talk of the whole community. And everybody will kind of look at you…you know like you did something awful!

In terms of gossip, Liz said that individuals are judged even if people just speculate that they are positive. Liz asserted:

> Most people don't, they don't say. You know, like if somebody is overweight and they see you start losing weight, even from any other kind of disease, they go, "He or she has AIDS.' You don't tell nobody. They see if you are losing weight or anything else. They are judging; thinking that's what you have.

Kiza agreed that this is a common practice. She stated:

> The wife and the husband might know, but they're not gonna tell the family. It's just like when something happen, people are just gonna guess that. Because most of the people that are dying back home, they just, at the end, they will know because the symptoms at the end. They will figure out, 'This is what it is.'

Mary spoke poignantly on this issue. Mary is a widow who has only ever been with her husband, yet she fears that if people knew she was HIV+, they would think she is a prostitute and mock her children accordingly. As evidenced by Mary, much of the concern over stigma and, therefore, their extreme reluctance to share their HIV status is due to concerns over their children's safety and well-being. In fact, the fear of the stigma is so tangible that Mary reported knowing someone in her home community who committed suicide after their HIV status was revealed. Therefore, she is afraid her children might do the same if her status was exposed. She explained the nature of the stigma as follows:

Mary: Oh! The mentality in my country, when you are HIV, that means you are a prostitute. And so, because I have a girl, nobody gonna come marry a prostitute's girl!

Joy: The daughter of a prostitute?

Mary: Yeah. So, you don't have time to explain to people , 'I was not.' I don't know. It is very shame. Very, very shame.

Joy: It sounds like you are also concerned about your children then. Like if people judge you, they will judge your children, as well.

Mary: Yeah. They say, 'Don't marry over there. Their mom is a prostitute.'

Mary continued to describe her fears and her desire to protect her children from any pain and suffering. She stated:

You know, people talk. If one person talk, and then just like that. Just that I am scared. Really scared (voice shaking)! For my kids, what they gonna be, how they gonna feel if people start talking about me? Because it's very hard what we live in my country. I don't want them again to be come to suffering.

Brenda Lynn had a similar fear. She revealed that she would be okay with people in the United States knowing her status, but she is afraid that someone from her home community living in the United States would share the information with people in her home country. Interestingly, her faith leader learned about her status because he was the person who originally brought her in for medical treatment when it was discovered she is

HIV+. But she said she does not worry about him telling others because he is from far away; not from her home village. In responding why she doesn't want anyone to know, not even in the United States, she explained she also has concern for the welfare of her children:

> *Brenda Lynn:* It is because when you tell them, when you tell anyone, they will take your story back home. Everyone has to hide his or her own problems. If you have any diseases like that you don't tell anyone. They will take the information back home and say that person has this illness, then the whole village will know and be talking about you.
>
> *Joy:* So that's your main fear. If the people here didn't tell anyone back home, you would be okay with them knowing?
>
> *Brenda Lynn:* Yes
>
> *Joy:* That would be okay if they knew?
>
> *Brenda Lynn:* If they didn't tell them it would be okay.
>
> *Joy:* What is the meaning of it for you, because you're not there anymore...
>
> *Brenda Lynn:* They will still talk. They will say that line, 'The mom went to America and she can't come (back) because she has HIV. She is ashamed to come back home. She will die there, and maybe that will bury her there.' They will mock my children back home.
>
> *Joy:* And you don't want that to happen.
>
> *Brenda Lynn:* No, I don't, that's why I never told anybody.

"Nobody likes to come near you.": Fear of Being Treated Differently

Most of the women expressed concerns about being treated differently, such as people trying to avoid physical touch, if their status is known. It appears that much of these hurtful behaviors are related to a lack of information or misinformation regarding how HIV is spread. Brenda Lynn confessed: "In our own village when this person has HIV they all begin to look at you differently. Nobody likes to come near you." The same is also true in Mary's experience. She stated: "Nobody gonna touch you. Maybe you got a cup, nobody's gonna touch. They'll say, 'No, don't touch it!'"

Kiza talked about the lack of accurate information and how it includes members of her community who have been educated, nonetheless, they still believe HIV can be transmitted through casual contact. She also discussed how being treated differently can add even more stress on you if you are positive:

> And some of them, they're not educated enough. It's like, when you are gonna touch something, they won't want to touch it. Or they wouldn't want to eat with you. They don't. I mean, because I see it, the way they treat other people. It's just like, they have a leper or something. So, you don't want to get to that point 'cause then it's gonna be more stress on you and you will be more miserable….And for the reason being, it's like, most people they're not really educated about HIV. They still think you can catch it by using the same bathroom. I mean that's even people who are educated. They come over here, they go to school, they finish school. But they still think that way. And some of them, they wouldn't even want to come to where you work because they think they're gonna become

contaminated. And some of them are even a member of your own family…. Yeah, maybe they don't even want to say, 'Hello' to you and shake your hand 'cause they're not at that level of education yet.

Liz shared that she believed these experiences of severe stigma against people who are HIV+ is actually a barrier for people to receive treatment. She asserted:

When somebody finds out somebody has HIV or AIDS, it's like you have a letter on your face. They treat you different. It's like getting scared of you. No one wants to be around you or nothing. You're just there. People run away from you. You can't talk to anybody about anything. If somebody finds out they have it, they just keep it quiet. Some go get medication, but most of them won't try anything because they don't want everybody coming to their house and they are taking medicine and find out about that they have been sick.

Relatedly, Michelle felt there is even stigma against HIV+ individuals among health care providers. When asked to clarify, she also explained a belief in her home country that people with HIV have done something wrong and that's why they contracted the virus. She said this belief exists in the United States as well:

Yeah, there's no question. There's no doubt. I have an uncle that is a doctor in (home country) and like he has stories. Like he'll say stuff like, 'You know, we had this person come in and they look like they had the "Bug"… or AIDS.' And, 'Oh my gosh! That's it. That's it for them! There is nothing I can do.' He doesn't

even want to like, you know, like take a second look… I don't know…something! But, there is stigma. And people we usually connect to like voodoo or, 'Oh, you did something bad and so this is happening to you.' But I've actually heard it here too. Like, (other youth who are HIV+), they'll tell me stuff like, 'Oh, you know…I am not accepted because that's what I deserve.' It's like, 'You deserve it? Nobody deserves to have a disease. Nobody deserves it.' ….I don't know, I feel like nobody ever...deserves that. It's crazy when I hear it. I feel like nobody deserves it.

"I don't see anybody that would tell. They don't tell. It's just a, 'No tell.'" : The Power of Silence

The majority of these women never told anyone about their disease status, even family members. Many of the women referred to the case manager as the one or one of the only people they have told. The majority of these women also kept experiences of intimate partner and sexual violence secret, especially after receiving a negative response after telling a trusted individual. Some of the women expressed a feeling that their status is easier to tell people who are not close to them than a loved one. Others have chosen a few individuals to share their status with, based on who needs to know their status and how much they trust them.

Kiza has not told anyone of her status, not even family members. She declared: "Back home they don't (tell). I don't see anybody that would tell. They don't tell. It's just a, 'No tell.'" Brenda Lynn said that she hasn't told anyone either, including her children,

friends or family members. She hasn't even told the friends with whom she is staying in the United States. She explained that there is a tight knit group of people from her home community here and people gossip a lot: "That's why I just hide it within myself, I don't even tell my kids." She is afraid "…they would go out and tell people this one has it."

When asked whether it was hard not to share their status with anyone, both Mary and Kiza seemed to feel that it was hard to be silent about it, but that they felt it was an easier option than being open about their status; this eased and reinforced their decision not to tell. Kiza also believes it is easier to tell people who are not close to her, like a case manager, for example, than a loved one. Again Kiza expressed a desire to protect her children and uses that as motivation to keep her secret. She explained:

> *Kiza:* I would say, to me, it's better for me not to (pause) because even if you talk with the family, it's just like it's a shame thing for the family. So, it's better for me not to put them in that situation. It's a shame. It's a worry.…
>
> *Joy:* Right, so do you have the urge to tell people, or, I mean, it sounds like, you just weigh the thought and you realize that these negative repercussions would happen, so, it gets rid of that urge or something like that?
>
> *Kiza:* Maybe, you would rather talk to somebody. I mean, I'd be okay to talk to the people like who are not close to me. But people who are close to me: no.

Later in the interview we came to this topic again and Kiza elaborated that sharing her status would also automatically expose her husband and family:

Kiza: But it's just like, when you talk about it, it's like it's not only me, it's also my family and my husband and it's just not right.

Joy: I see, because you would be exposing someone else and that's their decision if they want to expose themselves…

Kiza: And your family, you know, they really don't want anything like that (long pause). They just won't accept it, and they will be more miserable than you because you are already at the point where you accept it. You already know what's going on, but they are not on that level yet.

Joy: So even though you'd be okay with the situation, they're not going to be okay, and then it will kind of bring you back down?

Kiza: Yes. It's gonna be more painful for them than it is for me. So, I just don't want them… I mean… myself, if I really think about it, if it were just really up to me, I wouldn't care.

Joy: You would tell people?

Kiza: Yeah, but it's just gonna put them in a bad situation. And I don't want to put them in that. I mean, I love my family, I don't want to do that to them.

Mary did try to tell one of her children one day because she was so sick and a counselor recommended she tell someone. She also wanted to tell them because she is afraid that someday her child might discover her medicine and figure it out on their own. She described the interaction as follows: "I tell (them), 'I'm sick too much! I don't know

maybe it can be because your daddy was having too many…" And they said, 'Mommy, don't say that! Don't say that! You cannot have that.'

When asked if she knew of friends or other women in the community who are positive, Kiza stated: "They're not gonna tell you." She continued:

> *Kiza:* They would just suspect and nobody will come to you! Not especially with that question. But I already know there's quite a few of them that have passed away.
>
> *Joy:* Your friends or other women in the community that you know?
>
> *Kiza:* People that I know in my community that have passed away with it. So, I don't know if it is because they don't want to talk about it. And then…go through the treatment. All, I know, they got sick, real sick at certain point, or they waited too long before they started getting their treatment and it was too late.

While some women choose to keep their status secret, at least one woman, Michelle, was told by her family that she must keep her status secret due to the severe stigma they were afraid she would face. For her, keeping it a secret made her feel like her family was ashamed of her, though she later realized they were probably just trying to protect her from any discrimination she might face due to her status. She described it thus:

> *Michelle:* …the day that they told me I had HIV, my mom told me not to tell anybody. Like she said… 'Don't tell your (siblings). Don't tell anybody because they are going to treat you differently and they are not going to like you.' And I

didn't understand that because I felt like, 'Dang! What did I do wrong?' So, that night when I got home, the first person I told was my (sibling) (laughter). Like I pulled (them) aside and I'm like, 'Okay, this is gonna sound crazy. I don't know what it is…' 'Cause back there when you hear HIV, you think, 'Oh my God, this is a death sentence!'. So, I told (them) and (they) didn't believe me. (They were) like, 'Oh, I don't believe you! You want me to go ask mom?' And I'm like, 'Noooo! Don't! I'm not supposed to tell you!' So, (they) did some research and I talked to (them) every once in a while about it. 'Cause I, I don't know…I felt wrong hiding it from (them). That's why I felt like I needed to tell (them) because we tell each other everything. I felt like (they) needed to know and I needed somebody. But I feel like the reason why my parents didn't want…even to this day...they don't want me to be so public about it because stigma in Africa. Stigma. 'Cause growing up, I've heard so many stories about, 'Oh, this person got AIDS, and they just died.' It's crazy. So, I think stigma still exists. And I feel like my mom…she's seeing it and she's been there. She still thinks…Well, I guess it still exists. But she still thinks, you know, keep it a secret. People would treat you bad if they found out.

Joy: So, it sounds like she is trying to protect you from the stigma?

Michelle: Yessss? It took me a while to figure that out because at first I thought she was ashamed of me. You know. I mean, I know….(pause), I felt like, 'OK, if I can't tell the public, I understand. But, why not tell my (siblings)? Why not tell

my grandmother?' But, I don't know, I guess that's just her trying to protect me. But it took me a while to figure that out

Counter Narrative

Regardless of the intense pressure to keep their status secret, some women have chosen to share their status with select individuals, or for one woman, to live openly as HIV+. Because Michelle and Liz have been more open about their status, they have been able to benefit from receiving some services that the other women have not been able to access. For example, Michelle participated in a youth support group and Liz participated in a support group for adults. The other women have been too concerned about being exposed to participate in support groups. Michelle felt the youth group was helpful and would bring her sibling or husband to increase their understanding of HIV. For these women, who have chosen to share their status, it seems they have had relatively positive experiences. Even Mary, who is not open about her status, had a positive experience when a male relative of hers found out about her status. Without wanting to share her status with him, he found out about it because he lived here in the United States and when she got here, she was unable to navigate the medical system on her own. Even though she hadn't wanted to reveal her status, she was visibly moved by his comforting response as she reported it to me. He reassured her stating: "You're not gonna die. Because we all die in (their home country). Over here, they take care of medicine. Just feel like you are a normal person."

Liz, who went through counseling while staying at a domestic violence shelter is the most open about her status. She said: “If I feel stressed out, talk to some people about it, maybe call my case worker, or call my doctor. It keeps me going.” Here’s how Liz explained her evolution in terms of being open about her status:

> When I first found out, I didn’t want anybody knowing. I used to be scared when I come here (AIDS organization), if I see somebody from where I live or somewhere else. I was like, ‘Oh my God, they gonna go and tell me something. I don’t do that anymore. I had to get a lot of education from here, mostly from (case manager). She talked to me. And (another service organization), they used to have a group for women. And when we go to the doctor’s, we have people that come sometimes and talk to us. So I feel comfortable. If I feel comfortable talking about it, I tell somebody. A few of the people, they are not my friends. But you know, I can call them my friends because I felt comfortable enough to let them know. The people in my church, they know. It’s not a big deal like it was when I first found out. You couldn’t pinch me to tell anyone anything. If I went out to shop and see somebody I know, I would turn right back around and go home. I don’t do that anymore.

When I asked her what changed for her, her response revealed a larger growth process in which she feels better about herself as a whole, not only about her HIV status:

> Over here, it feels, I will say after some time I felt comfortable. I felt like I have some kind of, a little bit of power too. Like I can talk and people don’t judge. I am

still going to be okay. After everything is said and done, I am still going to be okay. It's like everywhere you go, people judge you, but here I feel comfortable. Even if somebody judges me or calls me a name or says something about me, I am still going to be okay. People won't be running away from me or neighbors moving out because of my illness. But back home, it's like, somebody says something smart to you about it and you just want to kill yourself or something. But I don't see it here.

Because she was diagnosed as a child, Michelle's parents know of her status. She also shared it with one of her siblings, her husband and one of his relatives. After telling her sibling, her husband was the next significant person she told. Here's how she described the process:

….for about five weeks, I kept thinking, 'Should I tell him? Should I not tell him? Should I just break up with him? No, no, no, no, no! Should I tell him?'…. And then this one time, I just said, 'Okay'. It just came out of nowhere. I was like, 'Look, I'm gonna tell you. I have something to tell you.' I told him and then he just like, he paused a few seconds and then he gave me a hug and then I started crying. I was like, 'Why are you giving me a hug?! You are not supposed to do this! You are supposed to walk away from me!' And then he told me that, you know, he said growing up he's been through so much…and people judged him. He wouldn't want to do that to somebody else. That was his reason. So, I explained to him my story, like what had happened, how I got it...He accepted it.

> Like he just said, 'Ok, we'll work this out together.' And that actually meant a lot to me.

After Michelle successfully shared her HIV status with her husband, at some point he asked her if he could tell his sibling. At first she was unsure. She told me that she selectively chooses who to share it with. This is how she described her selection process when her husband asked to share the information with his male relative:

> I have this thing where I need to know the type of person they are. 'Cause there are some people out there, that just say something. They will tell the whole world. And I didn't want that. So, I got to meet his (relative). And now the thing was, he told his (relative). But when I met his (relative), I was the one that explained it to him, how everything happened. And surprisingly, he felt like he had to tell me something too. I guess a secret; like he had to tell me a secret so we could be equal. At the same level.

Michelle confided that she is not always comfortable in sharing her status in every situation. She provided an example in which she attended a support group for HIV+ youth and ran into a woman she knew from her college. She said: "It was very awkward because I looked at her and she looked at me and we both knew... 'I know you have it, you know I have it'. And I was very nervous about it." Even though Michelle does not live openly as HIV+, she has chosen a few venues to talk publicly about her status in

order to help others. She provided some insight into how she makes decisions about with whom to share her status:

> ….I don't know, I feel like I can, like with you, I can be open. But as far as people who know me personally, I don't know. It's like a whole different level of like, if they don't accept you, it's like, I don't know. It sucks. But around here (AIDS organization), I don't know, I can be open and talk about HIV/AIDS. It took a lot out of me to do the (public speaking event). That took a lot! 'Cause I have limits. Like this woman came up to me saying she wants to do a documentary about me. I refused. 'Cause I have limits. I don't want the whole world to know. But I would rather a few people know if I'm gonna be around them and I'm gonna help them out. But sometimes it does get hard when I talk to my grandmother and she's asking me, 'Are you ok?' And I'm like 'Yeah, I'm fine.' Stuff like that…. But I can be open around here (AIDS organization). This is sort of like my safe haven. A place where I can just be myself. That's how I look at it. Outside of these doors (sigh), I mean, people hear me talk about it, they do. Like my husband, my (sibling), my parents…. I mean, my parents, for a while, my parents knew about it, but it was like a big elephant in the room. Nobody talked about it. They knew I was sick, they knew I'm taking medication. They made sure I was taking medications. But nobody talked about it. Every once in a while, I would talk to my (sibling) about it. But that was it. But when I came to like the youth group, I would like, I would talk too much. I was like, 'Ok, so, I want to do this…I want to do that….'

She later continued talking about this issue, this time in terms of her friends and classmates. She said:

> And I think maybe sometimes I don't want them (friends and classmates) to know because I feel like they don't need to know because it's (pause). It's like, if you have herpes, you don't tell people, 'Hey, I have herpes!' You know, you don't tell people, so I feel HIV is the same way. You don't tell people you have it. If they find out, okay….

"What happens in your household stays in there.": Silence for Sexual Violence

In addition to keeping their HIV status secret, many of the women also felt pressure to keep their histories of intimate partner violence, especially sexual violence secret. In Kiza's experience, sexual violence was not even acknowledged due to the belief that you can't be raped by an intimate partner. When it happens, it is not referred to as rape and isn't talked about. When asked how it affected her that it is not acceptable in her community to talk about sexual violence, Kiza stated:

> I wouldn't say that it affects me. I would just say it kept me in a point where I just don't, you know, I mean you want to talk about it. That's how I would think. But you don't know where to go, so you just keep quiet. It does even in my own relationship, you just say, 'This is weird.' But you keep it to yourself. Where would you go?!

Even when individuals do reach out and try to talk to someone about their experiences with sexual violence, they often don't receive a positive response. With regards to victimization by a relative as a child, Liz described the following experience:

> I told my grandmother. She just told me, you know, you were just kids playing. I said, 'No, it wasn't playing.' I told her exactly what happened and then she told me not to talk about that anymore. 'You were just, you know, him being a little boy playing.' I never talked about it until, like, I talked to my case worker about it.

Regarding being raped by an adult male community member when she was a teenager, she told her mother, aunt and uncle, but no one believed her. When Liz became pregnant from a rape that occurred in high school, she again tried telling her grandmother and was told to keep it to herself in order not to embarrass her family. She concluded:

> Yeah, you don't say much, if something happens it stays in the family. If you go and tell somebody else it embarrasses you family, so that's like you don't say much, you don't do much. What happens in your household stays in there. Whatever happens in the family you don't go and tell anybody else.

It seems that despite significant social and cultural barriers, as well as a history of being silenced, Liz refused to remain silent about the abuse she experienced. Instead, her resolve has only been reinforced. Liz stated: "If somebody is abusing me now, there is no way I am going to keep quiet. Or my child or somebody else I see, I will tell somebody

about it." Liz attributed this to personal growth, her stay at the domestic violence shelter, her interaction with her case manager and "knowing that I am not alone".

Counter Narrative

Brenda stated that in her community, she saw a lot of physical, emotional and sexual violence. Unlike the other women in this study, Brenda Lynn felt like she had an outlet to talk about her personal experiences with these issues. In addition to sometimes talking to her mom and one of her siblings, she explained that she and her friends would go out drinking together during which time they could talk openly. Though afterwards, they wouldn't bring it up again. She said: "…like my own friends would sit down and say, 'Do you know what happened last night? He did this.' They would tell me. I would say, 'This is what happened to me to last night: I had to leave the house, go outside and sleep somewhere…". Interestingly, this was something that could only be discussed when they were out drinking. She clarified:

> *Brenda Lynn:* When we are drinking, we can sit down and discuss everything.
>
> *Joy:* But when you are not drinking you wouldn't talk about it?
>
> *Brenda Lynn:* No. You don't talk.
>
> *Joy:* Okay, so it secret, except for these special times when you go...
>
> *Brenda Lynn:* (interrupting me) When you go to meet your friends to drink, then you have to bring something up to discuss and laugh together.
>
> *Joy:* And then no one talks about it after that?
>
> *Brenda Lynn:* No. It just ends there.

"…it's like I have two homes…": Binding Cultural Ties

Each of the women maintained very close ties to the community of their fellow countrymen here in the United States, as well as their family and neighbors back home. This is even true for Michelle, the youngest of all the participants who came to the United States at a very young age. She stated: "The way I see it, I was born there but it's like I have two homes because I came here at such a young age." One of the consequences of continuing to have binding cultural ties is that the women experienced social pressures to maintain modes of behavior that were acceptable in their community growing up.

Kiza explained this phenomenon when we began talking about decision-making with intimate partners and the influence of her family of origin. She seemed to believe that women face greater pressure to conform to rigidly defined norms and gender roles than men. Kiza explained that departures from accepted modes of behavior often lead to jokes and chastisement in order to put people back in their place:

> *Kiza:* Kind of. Most, I would say like, 80% you kind of stay with it (culture from home country). But some of them, a few people, they are trying to be a little bit Americanized maybe and trying to do it a little different. But when you do it a little bit different, the whole society will look at you like an outcast.
>
> *Joy:* Which society?
>
> *Kiza:* The people you know from your country and they live here. And they see you acting in a different way than the way we were brought up. I mean, they just look at you like an outcast. I mean, 'Why would you act in that way?' You know,

it's just…I mean some of them do it that don't care, but most of them, you kind of stick with your background.

The conversation continued:

Joy: Can you give me an example of something where you are saying, if you and your partner want to in a different way than the way you were raised back home.

Kiza: That pressure is more on the women, than on men. Men, they're still doing their macho things. But you, as a woman, if you are trying to kind of raise your voice or make decisions, trying to do this, everybody gonna look at you: 'What is wrong with you? That's not the way you were brought up. So, why are you trying to?'...

Joy: And then men trying to allow their partner to make more decisions, that would be okay because there is not as much pressure on men?

Kiza: It would be okay because...it would be okay. But, it's just like you know, people they would just come and try to make comments like, 'Your wife is the man now running the house. You don't run the house as a man.' They just make jokes like that.

Joy: And so, from the joke, you would know it is not okay?

Kiza: Well, some of them, they don't care. But it is quite, it is just a few that will find that they will let their wives make decisions. More likely the men do. Even over here.

Important Role of Churches

The women who participated in the study were generally women of faith. They were raised as Christian and although some of them switched sects, all currently practice their faith to a lesser or greater degree. In general, the women attended churches where the congregants were mostly African or African American. Their churches often provided essential support and were sources of strength for the women, however, their narratives also showed that the churches sometimes reinforced traditional gender norms and expectations.

Preserver of Cultural Norms

Some of the pressure Kiza discussed that individuals feel to maintain the norms of their countries of origin are placed on individuals from members of their churches. Each of the women in the study identified themselves as Christian and each women was practicing to a lesser or greater extent. Thus, the role of the church in their lives was important. In their narratives, this pressure did not seem to be coming directly from their church or the teachings of their faith, but instead from their fellow community members who attend the same church. Thus, as a place of congregation for members of their community, churches often as serve as the preserver of cultural ties and gender norms.

"By the grace of God, I started going to this church.": Resource for Strength and Community Support

The women in this study also mentioned churches and church members as being an incredible source of support. Churches and their members were involved in activities such as taking the women to appointments, as well as raising money to help one woman

pay for immigration related legal fees. Liz even stated: 'By the grace of God, I started going to this church' due to the gratitude she feels for the help with which her church has provided her. In addition, Brenda Lynn's faith leader is one of the only people who know about her status and he continues to assist her in making sure she is able to take care of her health.

"…if you believe in God, a lot of things can happen.": Outlet for Faith

As many of these women actively practiced their Christian faith, they would often offer a profession of faith while sharing stories of their struggles with HIV. Statements were made regarding gratitude to God for caring them through difficult times or for giving them a wake-up call so they can avoid greater difficulty in the future. For example, when discussing how difficult her job is, as well as constantly having to take HIV medication, Mary stated "I live by the grace of God." Liz also expressed gratitude to God for helping her through a difficult situation living in a domestic violence shelter: '… it was a bad situation, but it turned out to be something good from that bad situation. I am good where I am right now…and I am living every day. Thank God you know, for the blessings that he has blessed me and my kids.' At the end of her interview, I asked Liz if there is anything else important that I failed to ask her about, she said: "The only thing that I can say is if you believe in God, a lot of things can happen." Regarding severe physical abuse from her husband, forcing her to move to a shelter, she declared: "God blessed me enough. I got an apartment… It has been a real good thing and it just helps a lot."

COMMONALITIES BETWEEN THE AFRICAN AND THE AMERICAN CONTEXT

This study sought to highlight the contextual nature of women's sexual decision-making and reproductive health, including disease status, while exploring the role of gender inequality and gender-based violence. Although it is clear that sexuality is a contextual phenomenon, in conducting the interviews and the analysis, I was repeatedly struck by many of the commonalities between the experience of African-born and American-born women. While some of the details are different, patriarchal beliefs and practices are at the heart of virtually every society's structures. There are a plethora of examples, such as multiple, concurrent partners. In some of the African communities from which the women came, husbands are legally allowed to have multiple wives. This is a sanctioned cultural practice. Although having multiple wives is not a sanctioned marital practice in the United States, nonetheless, many men have multiple, concurrent sexual partners. Similar to the women in this study, it can also be difficult for women in the United States to ask their partner to use a condom or to refuse sex. Even though the United States has laws protecting women from marital rape (the majority of countries represented in this study do not), rape still occurs between married partners in the United States and often isn't recognized for what it is. Also, similar to the United States, many men do not face sanctions, other than divorce or the loss of a relationship, for the violence they commit within intimate relationships. There are also many parallels to gender roles in the United States, in which both sexual expectations and decision-making are circumscribed around men. Nonetheless, it is interesting that for some of the women,

particularly Liz, with exposure to mainstream United States society they begin to change their views regarding some of the unhealthy and even abusive behaviors their partners committed. Thus, it seemed mainstream United States society provided them with a new perspective on gender dynamics. Nonetheless, it is important that the women's risk did not end upon arriving in the United States. Regrettably, male dominance is also a part of mainstream United States society.

IDEAS FOR PREVENTION

As part of this study, I wanted to gain these women's input as to how to prevent the spread of HIV. Therefore, in addition to their personal narratives, the women in the study also offered a number of insightful suggestions. Their main suggestions focused on condoms, knowledge and testing. They also offered astute recommendations in terms of engaging in awareness techniques that adequately portray the risk of contracting HIV while letting people know they can still live full and healthy lives with a diagnosis of HIV+. Finally, they recommended offering services in non-descript locations that do not expose the HIV status of individuals seeking services, as well as having African and African immigrant role models to breakdown the stigmas against HIV+ individuals in their community.

"Just to use a condom. That's all.": Condoms, Knowledge and Testing

I asked each of the women if they had recommendations on how to prevent the spread of HIV, based on what would have been helpful for them, their family and/or community members. As mentioned, in general, their recommendations focused on condoms, education and testing. They also had insightful recommendations on the

delivery of HIV services. Brenda Lynn had a simple and straightforward recommendation: 'Just to use a condom. That's all.' Mary has already told her children to help protect themselves from HIV even though she is not open about her status with them. She explained: "When I talk to my kids, I just tell them, 'We are Christian. We don't have sex beside marriage. Even boy or girl. We have only after marriage. Be careful because there is HIV.' But I don't tell them about me."

Michelle stated that she was concerned about the myths about HIV in her home country, such as the belief that some men have that they can be cured of their HIV status by having sex with a virgin. Michelle said: "Culture, you know, it's part of culture" and felt those myths should be addressed. Marcia, the former doctor, recommends getting information out about HIV. She said: "The first thing is to get informed. The second thing is to tell people to use a condom." Marcia also recommended promoting condoms for birth control purposes, as well: "You can even think about it as using the condom for preventing HIV but also as a contraception method for all people, not only for people living with HIV." Liz's ideas for prevention also focused on education: "But the main thing I know for sure can help is education because the more people that learn about the illness the more they will know how to protect themselves." She added more specifics to her prevention plan as follows:

> Mostly education about the disease and how to protect yourself, like using protection. That would be very, very useful. Mostly education. A lot of men, they don't believe in using protection, so they think it's not okay to use any kind of protection. It's there, they know about it, but they don't believe in that. If they had

more education about that it might change a lot of things over there (home country). And getting tested, people get scared to get tested.

When asked if she would recommend different prevention strategies for the women back home than for women living in the United States, Liz felt that the strategies should be the same, though she felt women living in the United States were at an advantage in mitigating their risks because they are better able to say, 'No' to sex:

> No. It's just the same thing. I don't see anything different from there and here when it comes to using protection because you have to have education anyway, that's the number one thing. You have to know about how the disease is being contracted; what you have to do to protect yourself. Everything just has to be the same way, but to me it's like, over here the women understand better than the women over there because here women know a lot of things. They know how to say, 'No' to their boyfriends and husbands more than women there. A man has all the power over there, whatever he says goes when it comes to getting intimate, stuff like that. But here many more women know it's okay to say, 'No', or 'Not today', or 'We need to use protection' or 'We need to go get tested before we get together'. That would help.

Kiza recommended testing before marriage and stated that many of the churches in her home country are asking couples to get tested before getting married. Due to the important role faith communities play in this population, this seems to be an effective

method to use in Africa, as well as in African immigrant communities in the United States. Though she mentioned an important limitation:

> I mean, even though you do it, since most of them they go around even if you might do the test today, if they're still messing around, you're still gonna get it. But still, at least, you know you did your part. That's the only thing I'd say I should have done. Even though, they're gonna go around and do whatever. But at least I'd know I did the first part of knowing who I am getting involved with.

"I feel the scare tactics don't work…": Realistic Portrayal of HIV

Michelle had very insightful ideas in terms of prevention. She felt that awareness efforts should be focused around providing accurate information that acknowledges risk for HIV, as well as optimism regarding the ability to live a healthy life despite a diagnosis of HIV. She argued to end the scare tactics sometimes used to raise awareness of HIV:

> If I could think of a suggestion, I would probably just say that the younger generation are the ones getting it more. I feel like they, as far as awareness, people do it wrong. They do it more to scare people, like, 'Oh, if you get it, you are gonna die!' I feel like it's all wrong. And it's all blaming. All blaming one person or another. I feel like, I personally feel like, the only way…I mean the disease is not going to go away 100%. But I feel like the one way to lower it is to make people accept it. Does that make sense? Like, 'Out of sight, out of mind.' People will say, 'Oh, I will have sex with this person without a condom. I don't care' even though they know there are risks like HIV or STDs or infections. They don't

think about it. But I feel like, I don't know how to say this but, I feel like it needs to be accepted by everybody. There is stuff like that. You are gonna get it if you don't do this. And that's what people don't do. People don't accept it. Even when they get it, they still don't accept it. That it exists.

Our discussion continued and she elaborated:

Michelle: I feel the scare tactics don't work because once people get them, they don't want to know. They don't want to get tested. They don't want to take medication. Because of those things that they hear.... It's like the education is not there to handle the disease ….But I feel like, people don't want to know about AIDS because they get scared and they don't want to know. So, they don't accept it.

Joy: So, do you think if the information is more realistic, to say, 'This is the risk, but if you get it, you can manage it, with you know, medication, a healthy life style'... Do you think people may be more proactive in like being tested and being careful?

Michelle: Yeah, like when people see me, they look at me and they don't think I have it ….They say, that I give them hope because their thing is, 'Once you have HIV, that's it for you!' That's what everybody says, 'That's it for you.' So, when they see a person like me whose accepted, 'Oh, I have it, I have to deal with it.' Obviously, you can survive with it. You can be healthier than the average person. So, I feel like acceptance is the key. But I don't know how they could do it. I

don't know if a lot of people ...a lot of positive people would want to go out and be a.. not a showcase…I don't know!

Joy: But, you think that helps people who are positive, just regular community members, everyone to see, people who are positive and healthy, and…?

Michelle: Yeah.

Joy: That's a good idea.

Michelle: I feel like yeah. That would help a lot. Like I give people hope and I feel like I'm still going through stuff. A lot of stuff! But, they think I am 100% fine. And I tell them I am not. I tell them that it is something you are going to deal with for a really long time. But you have to get to a certain level where it does not affect you so much, like take over your whole life. But HIV is not a death sentence. So, people need to accept that, 'I have HIV. Let me just take the medication.' 'Nobody told you that you have two weeks to live. Pretty much, nobody has given you a deadline. You make your own deadline.' And two, 'You don't live in a third world country where you live in a tiny little village and the closest hospital is 30 miles away…. But you live in a country where it's developed. You have the technology, the medication. You have …I feel like America, the UK, and Australia, they have the places where people are more accepting. That's why you see lower HIV rates than you see in Africa. Nobody…I mean, I mean, I understand, people here don't accept it 100%, but it's like, 'OK, you have it. You know you are going to survive.'

"We are not exposed to that yet. For somebody to go on TV and claim, like Magic Johnson, I'm HIV+.": Role Models Speaking Out

Similar to what Michelle experienced with people being inspired by her and encouraged by her health, as well as her optimistic perspective, Kiza stated that there needs to be a Magic Johnson-like figure from her home country to bring awareness to the issue. She added: "We are not at that level. I wish it could be that way, I mean you know…I would stand up and talk about it. But it's just like, when you talk about it, it's like it's not only me; it's also my family and my husband and it's just not right." It is interesting to note that these women have pinpointed a need for these types of role models, because even though they were participating in this study confidentially, I feel they are already serving in this pioneering capacity for their community by having the courage to share their stories.

"Oh, it was just hell for me! I was very scared!": Non-identifying Facilities

Mary shared information about HIV treatment efforts in her home country as an example of what not to do. She described a situation in which a missionary group which she believed was from the United States was bringing medicine to her country. She said: "They bring medicine, but it's not secret. You just go and then you put your line. You are exposed. Everybody knows that. You go get medicine." She related a story about a woman she knows who received that medicine and then how hard it became for her when everyone knew her status. Her community members would warn each other to be careful of her. Similarly, Mary expressed fears in going to (the AIDS organization). She said:

> Yeah, before, it was very hard for me! When I come to get out of my car, I am very scared! When I have an appointment, to come before I finish and I go. Oh, it was just hell for me! I was very scared! But, I don't know, it just got helping me, never see somebody who knows me. Yeah.

Mary argued for service provision at an anonymous, non-identifying location. Her case manager offered her the opportunity to attend a support group with some people from her home country, but she stated: "No, I am not yet ready for that." Even if it was people from another African nation, she would be unwilling to attend. For justification, she told a story of a woman from her church who is from another African nation. She was open about her status and now she is mocked and laughed at. So, when the woman shared her status with her, Mary did not share hers. Kiza agreed and detailed the difficulty in recruiting HIV+ African immigrants:

> Well, of course over there, they need services. But over here, even if you know, somebody wants to recruit them, it's going to be really hard. Really hard, especially when they know it's a place where other people with HIV. So, they are afraid they might meet somebody that they know. It's just the thing. They think, you know, you hear them talk about: 'Well, they should have something more private than just make it because it's an open thing'….The way you walk in and everybody looks at you kind of funny. But if they could have something, you know, some people might have their private doctor, they go over there then it's not a big scene. But something like this, it's a big scene!

Chapter Five: Discussion

In conducting this study, I endeavored to answer several broad research questions regarding the role of gender inequality, gender-based violence and contextual factors in risk for contracting HIV. In doing so, I uncovered three overarching themes: marriage as a vulnerable status, gender inequality and gender-based violence as social norms, and the cycle of stigma and silence. This chapter discusses the study's main findings in relation to the scholarly literature, highlights research surprises and offers areas for further exploration. Finally, the chapter ends with a discussion on the relevance of Feminist Theory, Critical Race Theory and the Theory of Gender and Power in relation to the narratives shared by the study's research participants.

ATTENDING TO RESEARCH FINDINGS

Thanks to the courage and bravery of the women who participated in the study, we have gained considerable insight the role of gender-based violence and inequality on the disease status of HIV+ African immigrant women. Their unique experiences and incredible insights shed light on the transmission of HIV in their community, as well as in the general population by helping us understand some of the fundamental gender dynamics related to the spread of the virus. Thus, their wisdom and insight have paved the way for recommendations on preventing the spread of HIV in their communities in the United States, as well as abroad.

Marriage as a Vulnerable Status

The study's main finding is that marriage is a vulnerable status for the women who participated in this study. Four of the six women in the study believe they contracted

or most likely contracted HIV from their husbands/long-term partners through heterosexual sex. The other two women contracted HIV as children through other means. Gender norms, roles and expectations were clearly defined with women facing considerable pressure to marry, stay married and have children. Once married, limits were put on the women's sexual decision-making. The consensus of the women seemed to be that men hold most of the power in terms of sexual decision-making. In fact, many issues, such as condom use are not even discussed. Oftentimes, the women were aware, at least partially, that their partners' behavior, such as having multiple concurrent partners was putting them at risk. Nonetheless, established gender norms dictated that they were to accept instead of refuse this behavior. These norms made it difficult for women to refuse sex or insist upon condom use.

Their experiences are backed by research. Research on HIV has shown that married women are at risk for contracting HIV due to barriers they face in practicing safe sex. In terms of married women having difficulties saying, "No" to sex, a study exploring the association between sexual violence and risk for contracting HIV in a South African health clinic highlighted the severity of the risk when a research participant repeated the following local proverb: "A woman's grave is in marriage" (Madzimbalale, et al., 2012). Moreover, a study exploring reproductive health and intimate partner violence in Zimbabwe found that social norms, often perpetuated through families, affect individual's sexual decision-making. For example, women were instructed to fulfill their wifely duties and not to refuse sex to their husbands (Shamu, Abrahams, Temmerman, Shefer, & Zarowsky, 2012). The study also found that women often feel pressure to have sex with

an unfaithful partner in order to maintain their sexual interest when they have multiple concurrent partners (Shamu, et al., 2012). Similar to the findings of this study, a study exploring the association between sexual violence and risk for contracting HIV in a South African health clinic found that the concept of marital rape is not accepted and there is a belief that husbands cannot rape their wives (Madzimbalale, et al., 2012).

These findings are not limited to African-born women. Research has shown that African-born and American-born women face many of the same relationship dynamics putting married women and women in long-term committed relationships at risk. For example, an HIV-related study of African immigrants living in a large metropolitan area of Texas found that married women used condoms less consistently than unmarried women (Rosenthal, et al., 2003). The study also found that men were more likely to use condoms than women, the study did not clarify the reason for the difference, but it may be because of relationship dynamics in which men are having concurrent partners and, thus, trying to protect themselves from STIs and unintended pregnancies. In addition, a study on the relationship between STIs and intimate partner violence among Mexican American and African American women found results similar to this study that women who ask their partners to use condoms are often accused of cheating (Gomez, 2011).

Unfortunately, it is difficult for women to safely change these dynamics once they have been learned in childhood and reinforced in intimate relationships as evidenced by the conclusions made by researchers from a South African study on HIV. They stated:

> The potential for women to effectively reduce their risk for HIV and other STIs is seriously undermined by socially constructed gender roles and sexual scripts.

> Women who suggest using condoms with a resistant sex partner may experience adverse consequences of threatening the masculinity of their partner, including raising partner suspicion about monogamy or sexual history, thus finding themselves vulnerable to further violence, being rejected, and potentially losing financial support from their male partners (Kalichman, et al., 2008, p. 257).

Gender Inequality and Gender-based Violence as Social Norms

The narratives of the women who participated in the study were rife with experiences of gender inequality. The women in the study spoke of gender inequality less in terms of educational and economic opportunity and more in terms of social interactions. Their narratives showed how accepted gender norms, such as male-dominated decision-making, observed in their families of origin, and in the larger community, affect their sexual decision-making in their intimate relationships. Their narratives also introduced us to their experiences of sexual, physical and emotional abuse, as well as physical and emotional neglect.

Similar to what the women in this study shared, a study on Sri Lankan immigrants found that female and male study participants learned gender roles (i.e., women are responsible for the care of children) in their youth in their home country and tended to enact those roles in their adulthood (Guruge, Khanlou, & Gastaldo, 2009). This is particularly dangerous in terms of sexual and reproductive health, as traditional family structures and gender roles put women at risk for contracting STIs (Champion & Shain, 1998), as well as rape by reinforcing beliefs that men should dominate women in relationships (Jewkes, 2001 as cited in Kalichman, et al., 2008). These power differences

also make it easier for men to refuse to use condoms and have multiple sexual partners (Kalichman, et al., 2008).

The recent literature on HIV and prevention also shows the influence of gender roles and inequality on women's reproductive health, such as disease status. A study examining the relationship between gender inequity and risk for HIV infection in Botswana and Swaziland found that higher levels of gender inequity were linked to sexual violence, as well as risky sexual behavior, thus putting women at risk for contracting HIV (Shannon, et al., 2012). Similar to the results of this study, Shannon and colleagues (2012) also found that gender inequality enhances the economic dependence women have on men and, thereby, increases the likelihood they will engage in survival sex.

Regrettably, similar to women throughout the world, the majority of the women who participated in this study were not immune to experiencing violence, particularly at the hand of an intimate partner. The women experienced physical and emotional abuse by husbands and partners. They also experienced sexual violence perpetrated mainly by intimate partners. At times their partners were physically and emotionally neglectful making the women feel invisible and uncared for.

Incidences of intimate partner violence, like those described by the women in this study, also put survivors at risk for contracting HIV. A large South African study found a positive relationship between intimate partner violence and HIV among women who experienced gender inequality, as well as intimate partner violence in their relationships (Jewkes, Dunkle, Nduna, & Shai, 2010). Furthermore, their results showed that these

cases made up a considerable share of HIV infections (Jewkes, et al., 2010). Similarly, Champion and Shain (1998) found that survivors of intimate partner violence faced significant barriers in asking their partners to use condoms, especially in circumstances where the gender dynamics were similar to those experienced in their families of origin. In part, the research suggests that HIV rates are higher among women who experience intimate partner violence because fear of violent reprisals often prevents from being able to convince their partners to engage in safe sex (Madzimbalale, et al., 2012). This is compounded by the fact that sexually aggressive men are also more likely to engage in risky sexual behavior (UNFPA, 2010; WHO, 2010) and are at the highest risk for contracting HIV (Kalichman, et al., 2008). Thus, survivors' risk is increased yet again due to the risky sexual behaviors in which perpetrators engage.

It is important to note that these gender dynamics are not unique to Africa, they simply play out differently in different contexts. Interestingly, focus groups conducted in the United States with American-born survivors of intimate partner violence revealed that they experienced many of the same issues. Rountree and Mulraney (2010) found physical violence increased the women's risk for contracting HIV, as did sexually violent and coercive behavior on the part of their partners, as well as having relationships with men who had multiple sex partners.

Cycle of Stigma and Silence

The women who participated in this study shed light on a number of issues related to their HIV status. Most prominently, their narratives included powerful and poignant examples of HIV-related stigma. This stigma led most of the women to fear becoming

social outcasts should their seropositive status be revealed. In general, with a few carefully chosen exceptions, this led the women to keep their status carefully hidden away. In keeping their status hidden, many sought to protect their children from the bullying and gossip they would most likely face if their mother's status was revealed. Due to gossip and the close knit nature of their community of countrymen here in the United States, they worried that knowledge of their status might make its way back to their countries of origin. For some of the women, the unfortunate consequence of this stigma and ensuing silence, is that they were unable to benefit from support groups for fear of being exposed.

Research on HIV highlights the significant role stigma plays in the lives of HIV+ individuals, both in Africa and the United States. A study of African immigrant women living in the United States found that the women believed that HIV+ individuals would be feared, isolated and cast off (Foley, 2005). This fear of rejection prevented people from disclosing their status. The researchers explained: "Since social life and social relations are central to many African cultures, isolation from family members and friends is as terrifying as contracting the virus" (Foley, 2005, p. 1040). This finding seems to reflect the experiences of the women who participated in this study. Similarly, in a HIV-related study of African immigrants in the southwestern United States, researchers found that when asked: "How do people in your community/culture commonly react to and treat people with HIV disease", approximately two-thirds of the 309 respondents stated "with fear, avoidance, and secrecy" (Rosenthal, et al., 2003, p. 575). In addition, almost half of the respondents said that community members would gossip about their status and isolate

them. Interestingly, the study also found that women perceived stigma levels to be higher than men did (Rosenthal, et al., 2003). This may be related to the more narrowly approved sexual behavior for women. Furthermore, the perceived level of stigma against HIV+ individuals decreased the longer individuals resided in the United States, perhaps indicating that stigmatization levels were higher in their home countries (Rosenthal, et al., 2003).

There are several factors that are linked to the overwhelming stigma associated with HIV among African and African immigrant communities. It has been shown that some of the stigma is due "largely because of the associations between HIV, sex and promiscuity, and death" (Foley, 2005, p. 1036). Thus, HIV is seen as a moral issue that impacts entire family systems. Hence the women in this study's worry about the reputation of their children, as research has shown that children affected or orphaned by HIV/AIDS also face intense stigma (Skinner & Mfecane, 2012). Some of the overwhelming stigma also seemed to be associated with lack of information about the virus and how it is contracted (Foley, 2005), thus increasing people's unwarranted fears of being infected through casual contact.

Studies on HIV+ African immigrant women show that perceived stigma against HIV+ individuals discourages women from disclosing their status to loved ones (Callin, Green, Hetherton, & Brook, 2007). In these cases, individuals make careful, reasoned decisions not to share their status (Callin, et al., 2007; Foley, 2005). Similarly, a study of HIV+ African immigrant women living in the United States found that the women's main concerns were related to confidentiality and not having their HIV status exposed (Foley,

2005). Like the women in this study, these women also did not disclose their status to friends, family and loved ones for fear of social isolation. These women also talked about gossip, rumors and guessing. This fear led to social isolation regardless of whether the stigma was real or perceived (Anderson & Doyal, 2004). Stigma, and the resulting fear of disclosure, has significant impact on HIV+ individuals, including reducing their help seeking behavior for fear of having their diagnosis exposed (Foley, 2005). This prevents them from receiving the social support that is so vital in coping with the infection and potential disease (Skinner & Mfecane, 2012). Finally, a review of the literature on HIV stigma in South African found that stigma against individuals with HIV/AIDS actually promotes the spread of the epidemic by undermining prevention efforts and preventing people from being tested and treated (Skinner & Mfecane, 2012). These finding are consistent with the stories of the women interviewed in this study.

RESEARCH SURPRISES

The main research surprise this study produced was the fact that marriage is a vulnerable state for women. Conventional thinking often posits marriage as a protective factor for women when it comes to sexual risk behavior. However, in the case of the women in this study, it is not the women's sexual risk behavior that is leading to HIV infection, it is the behavior of their spouses/partners. This finding has important implications for HIV prevention and treatment. Researchers and practitioners alike must ask themselves how to protect women from the obstacles they face to safeguard their sexual health upon marriage.

The second research surprise revealed by this study's findings was that contextual factors, such as poverty and migration, did not play a prominent role in their stories. As previously mentioned, this may be due in part to my interview questions which tended to focus on interpersonal relationships. It may also be due to fact that the sample of women recruited into the study did not include refugee women, who one could expect would have more prolonged migration experiences. The women were also wealthier than expected and, thus, were more concerned about the educational and economic opportunities for their female family and community members in their home countries. They felt lack of opportunities for women to build their financial independence put them at risk for enduring unhealthy and sexually risky relationships, thus increasing their risk for contracting HIV. For the women who participated in the study, it seemed that the question of who controlled the household finances was more important than how much income they had as a family. Again, this posits questions for researchers and practitioners in terms of how to support women in obtaining financial decision-making powers within their long-term intimate relationships.

AREAS FOR FURTHER EXPLORATION

This was an exploratory research study, therefore, much was learned in terms of the process through which the study was conducted, as well as the content that was examined. Below are some thoughts regarding areas for further exploration in future research.

Social Identity beyond Gender

Although the theoretical framework employed in this study included Critical Race Theory, the focus of the study was on the role of gender-based violence and gender inequality on risk for HIV. Due to methodological limitations, such as only having one interview with each woman, it was necessary to focus interview questions on the study's primary research aims. Thus, other issues besides gender, such as race were only explored in a peripheral manner in this study. This is a limitation, as exploring these areas may have provided important contextual information on the lives of the women who participated in the study. This design was not meant to diminish the importance of these issues in any way, but instead to maintain the study's research focus given the limits on face-to-face interview time with the participants. In retrospect, there were questions that were not asked in this study, such as the women's experiences as Black immigrant women from African nations and speakers of English as a second language, that could have enhanced our understanding of their lived experiences. For example, one woman stated that she used to attend Catholic religious services in her country of origin, however, in the United States she chooses to attend Baptist religious services because she didn't see many Blacks in her local Catholic church. Further exploration might have shed light on their lives in terms of race and immigration status and how better to meet their unique service needs.

Moreover, methodological considerations were made in order to protect the strict confidentiality of the women in this study. For example, despite its relevance and influence, I was not able to reveal the country of origin of each woman. Although I was

able to list the nations that were represented in this study, I was not able to link the country of origin to a particular woman. This has important implications because this contextual piece regarding her social identity as an African woman was not explored. In choosing not to make this connection in order to safeguard the women's confidentiality, I in no way intended to take away from the importance of each woman's unique identity. Nonetheless, the reality of the urgent need to protect the women's confidentiality had to be respected. It is hoped that future research will able to dedicate more time and attention to these influential aspects of women's social identity. Furthermore, the ability to link women's experiences of gender-based violence and inequality with their countries of origin would provide useful information in terms of illustrating the *regional patriarchies* that create a patchwork of inequality for women living in patriarchal societies.

Social Policy as a Key Contextual Issue

In designing this research study, I conceptualized contextual factors relevant to the women's lives mainly in terms of poverty and migration. This conceptualization was based on a synthesis of the scholarly literature regarding risk factors related to the contraction of HIV. These contextual factors did not appear as prominently in the women's stories as I had previously expected. As mentioned, some of this has to do with the study sample, as it did not include refugee women. However, in reflecting on structural issues affecting women's risk levels, social policy emerged as a key issue, even though it was not mentioned specifically in the women's narratives. In contemplating the women's lives and in listening to their narratives, it is quite striking that the women did not discuss social policies or the institutions, such as courts, that enforce them. For

example, the narratives include examples of women turning to family members or friends for assistance following incidences of domestic violence. However, with the exception of Liz who sought shelter at a domestic violence shelter, the women did not describe contacting the police. Thankfully, one woman cited a growing awareness among women from her country of origin that they can turn to police in some circumstances for assistance. This lack of discussion of social policies and institutions leads us to question the relevance they play in these women's lives and in safeguarding their reproductive health.

Unfortunately, a comparative study of the relevant social policies from the five nations represented in this study is beyond the scope of this study. Nonetheless, this study sheds light on the fact that this is an area that deserves further exploration. For instance, did the women in the study not turn to social institutions, like law enforcement and the courts, because social policies protecting the rights of women are not codified in their countries of origin and/or because they are not adequately enforced? If so, how can this situation be improved? There are a plethora of social policy areas that affect women and their ability to protect their reproductive health. These areas may include laws prohibiting violence against women, including sexual violence, and promoting their reproductive choice. The findings from this study show that marriage is a vulnerable status for women. Therefore, social policies, such as those governing marriage and children, could have a significant impact on women's risk for contracting HIV. For example, if a woman's husband is having multiple, concurrent partners is she able to receive alimony and/or child support should she choose to reduce her risk by leaving her partner? These types of

policies would greatly increase the options available to her. In addition, do protections for women extend to married women, such as the prohibition on marital rape? Policies to reduce women's risk for HIV should be interpreted broadly and may also include laws that promote women's economic opportunity and, therefore, reduce their financial dependence on men, such as legislation supporting equal pay and educational opportunities for women.

ATTENDING TO THEORY

This study was guided by a theoretical framework composed of: Feminist Theory, Critical Race Theory and the Theory of Power and Gender. This framework guided the exploration of how social and economic factors (such as race and class) related to one's vulnerability for experiencing gender inequality and gender-based violence, as well as various negative reproductive health outcomes, such as HIV infection. Based on critical theories, the theoretical framework contextualized the lived experiences of the women participating in the study. The following section discusses the relevance of each of the theories to the experiences revealed in the women's narratives.

Feminist Theory

Feminist Theory was very useful in this study in terms of understanding the impact living in patriarchal societies has on women and, in particular, their reproductive health and disease status. Virtually all societies are male-dominated, however, the exact dynamics of how gender inequalities are enacted varies. Utilizing a Feminist lens allowed the study to highlight the unique gender roles and norms that heightened and shaped the inequality felt by these women. Feminist theory also increased our understanding of how

gender inequality provides an environment that is conducive to gender-based violence and how these factors come together to put women at risk for contracting HIV, for example, reinforcing beliefs that males should be sexually aggressive.

Critical Race Theory

In terms of Critical Race Theory, this theory did not come across in the study as much as expected. Critical Race Theory highlights the institutionalization of racism and inequality, as well as calls attention to intersecting forms of oppression. Prior to conducting this study, I had expected to have a sample of women that consisted largely of refugees. Thus, I expected the women to share narratives centered around poverty and migration. Interestingly, however, the sample of women included in this study did not include refugees, although one woman is in the process of seeking asylum, she did not have an extended period of temporary resettlement in another country. Thus, she did not experience overcrowded housing in refugee camps and other factors that would mimic the experience of life as a refugee. Furthermore, although Critical Race Theory draws attention to institutionalized oppression, these women's narratives focused on the interpersonal, as opposed to the institutional. Perhaps future research can include interview questions more directly focused at teasing out institutionalized forms of oppression in these women's lives. Nonetheless, Critical Race Theory was useful in that it pointed to the importance of testimony based on one's lived experience and hence theoretically support the use of narrative analysis as the appropriate methodological choice for this study.

Theory of Gender and Power

Similar to Feminist Theory, the Theory of Gender and Power how gender inequality and gender-based violence increase women's risk for contracting HIV. The theory provides insight into the manner in which inequalities play out in intimate relationships. Thus, it proved useful in illuminating how forces of oppression and inequality play out in the context of intimate partnerships and affect sexual decision-making and, thus, reproductive health. This study was able to show how gendered power dynamics impeded women's ability to engage in equal sexual decision-making with their partners. Instead, they often found themselves putting their health at risk in order to engage in behaviors (such as having unprotected sex) which would allow them to maintain the sexual interest of their partners; behavior that would not be necessary in a context where women's relationship status was not dependent on pleasing her partner without concern for her own well-being.

LESSONS LEARNED FROM THIS STUDY

This study exploring the role of gender-based violence and inequality on the reproductive health and disease status of HIV+ African immigrant women shows that in contrast to common perceptions that marriage is a protective factor when it comes to STIs, for these women it was actually a risk factor in relation to contracting HIV, as it complicates women's ability to say, "No" to sex, ask their partner to use condoms or not engage in sexual activity with partners who have multiple concurrent partners. This study also shows how gender inequality and gender-based violence are normalized in communities, as well as some families of origin, and how this socialization affects

women's relationships with their intimate partners in ways that put them at risk for contracting HIV, such as limiting their role in sexual decision-making. Finally, the study shows that the intense stigma surrounding HIV for African immigrant women isolates them socially and prevents them from receiving support to cope with their diagnosis. Thus, the culture of silence around HIV interferes with HIV prevention efforts. These findings teach much about the experiences of African immigrant women related to HIV and grant potential insight into the dynamics of HIV contraction for all women. Finally, Feminist Theory, the Theory of Gender and Power and, to a lesser extent, Critical Race Theory, were useful in analyzing the narratives provided by the study participants. The theories provided a format to give voice to the experiences of multiply marginalized women while recognizing that placing previously marginalized groups in the center of the analysis can provide life-saving information regarding preventing the spread of HIV.

Chapter Six: Implications and Conclusion

RELEVANCE TO SOCIAL WORK PRACTICE AND RESEARCH

This was a small exploratory qualitative research study. Nonetheless, the study's findings point to important implications for HIV prevention and treatment, as well as policy and future research. These implications should be examined within the context of social work, as social workers have a variety of opportunities to intervene in the lives of HIV+ immigrant women. Social workers might provide services to these individuals in any of the following settings: victim services, hospital-based social work, policy advocacy and/or refugee and immigrant services. Furthermore, social workers have a key role to play in developing effective prevention strategies, as well as individually tailored treatment options. Thus, this section will discuss practice implications to improve HIV prevention and treatment. Policy and research implications will also be addressed.

PRACTICE IMPLICATIONS

In terms of the implications of this study's findings, the most relevant information is probably related to the ideas for prevention that the women in the study recommended themselves. Some of their ideas, such as promoting condom use, knowledge and testing are standard HIV prevention methods. However, they also provided insightful recommendations catered to the unique needs of their community. Their ideas regarding improving awareness building strategies and working with the African immigrant community to increase their involvement are discussed. I also expand on their statements regarding the connection between gender-based violence and risk for contracting HIV in

order to offer additional prevention recommendations. The treatment implications prompted by this research include improving the response to service requests, providing culturally appropriate interventions and offering services at anonymous locations.

Prevention

Create Fair and Realistic Awareness Building Campaigns

This recommendation is due to Michelle's wise observations about current HIV awareness building campaigns. She stated that campaigns should avoid what she called "scare tactics". In her opinion, some awareness strategies sensationalize the consequences of contracting HIV. In her opinion, this is commonly done when trying to convince youth to avoid risky sexual behavior and includes misrepresenting HIV as AIDS and branding it, in her words, as a "death sentence." She feels that scaring individuals, including youth, doesn't not necessarily change sexual behavior, but does make people fear HIV so much that they prefer to ignore its existence, pretending that it cannot happen to them. Fear that HIV infection will lead to illness and death deters some people from being tested because they feel they would not be able to handle knowing they have a "deadly disease." Based on this research I agree with Michelle's recommendation that a more effective approach would be to adequately portray the risk of contracting HIV while letting people know they can still live full and healthy lives if they become infected. It is hoped this approach would lead people to make safe and healthy choices regarding their sexual behavior, choose to have their status tested and, if they test positive, to feel confident that with the right support and tools they can continue to live a rewarding life. Furthermore, by

decoupling HIV with threats of disease and death, this strategy may help in reducing the stigma against HIV+ individuals.

Increase Involvement of the African Immigrant Community

As previously mentioned, each of the women in the study identified themselves as Christian and each woman was practicing their faith to a lesser or greater extent. Most of the women attended churches serving largely African immigrant and African American congregations. Churches played different roles in the women's lives. Some expressed gratitude for their church, its members and their support. Others highlighted the fact that because they are a place of congregation for individuals from their home countries, churches can be a place where gender roles and stereotypes are reinforced and perpetuated. Only Liz was able to participate in her congregation as an openly positive woman. Thus, churches serving the African immigrant community could be key centers of outreach to overcome the stigma associated with HIV, as well as engage in prevention activities. In addition to churches, other organizations including businesses who serve and employers who hire African immigrants could act as key stakeholders in prevention and awareness building activities. HIV prevention researchers have found that in order to be effective it is essential to work with immigrant refugee communities and their religious (Hynes & Cardozo, 2000) and secular (Foley, 2005) leaders.

Finally, the women recommended having African and African immigrant role models who are HIV+ to breakdown the stigmas against HIV+ individuals in their community. Kiza specifically mentioned the need for a Magic Johnson-like figure to which their community can relate in order to overcome the overwhelming stigma. Thus, it

is important to support individuals who freely chose to disclose their status, to do so safely. Although their identity remains confidential, it is my hope that the stories of the women who participated in this study can be a stepping stone for breaking down the stigma by providing stories of strength with which people in their community can identify.

Reduce Gender Inequality and Gender-based Violence

Perhaps the greatest lesson this study can provide is that reducing gender inequality and gender-based violence is an essential strategy in HIV prevention. The World Health Organization has published recommendations for the member states of the United Nations stating that promoting gender equality and ending violence against women are key HIV prevention strategies (WHO, 2010) that require cultural and gender sensitivity *(*United Nations General Assembly, 2001). The World Health Organization recognizes the particular influence of sexual violence and has asserted "HIV programs should include activities to raise awareness and promote the prevention of sexual violence as well as intimate partner violence, recognize the extent to which sexual activity is forced or coerced and explicitly address issues of consent and coercion" (WHO, 2005, p. 24). Thus, violence against women should not be viewed as an individual problem, but instead as a social issue requiring collective change (Kalichman, et al., 2008; Mahmood, 2005).

Targeting men. The work to promote gender equality and end gender-based violence is a long-term strategy that will require society to change its views on women. In order to more effectively target men, researchers need to first gain a better understanding

of why men engage in particular behaviors within specific social contexts (González-López, personal communication, August 1, 2013). As Amaro, Raj and Reed (2001) argued: "…the social construction of women's sexuality is highly related to the high STD and HIV rates among women. Women's lower power and status, sexual violence against women, and gender role stereotypes prevent women's control of their own bodies" (p. 329). Research has concluded that the HIV epidemic and the scourge of rape are closely connected in countries such as South Africa (Kalichman, et al., 2008). Hence, we must stop socializing men to be dominant and women to be sexually passive (Madzimbalale, et al., 2012). These systemic changes would empower women to protect their sexual health. Thus, we can see that prevention strategies that target men can also save the lives of women (Gomez, 2011).

Train Domestic Violence/Sexual Assault Service Providers and Health Care Workers

When violence against women does occur, it is imperative that survivors receive effective services. In order to do so effectively, domestic violence and sexual assault service providers should receive cross-training from medical providers and visa versa (McMahon, et al., 2000). Women seeking services from domestic violence and/or sexual assault service providers should receive education on their risk for contracting STIs, including HIV. These service providers must be aware of women's risk for contracting STIs (Rountree & Mulraney, 2010). Service providers should also be familiar with various contraceptive options, such as condoms use (UNFPA, 2010), and be able to offer targeted referrals to empower women to take care of their reproductive health. They should also be able to support the women they service in increasing their health literacy.

As gender-based violence is associated with reproductive health issues, including HIV, it is essential that the health care system be responsive, as this is a system with which the women often interact (ARROWS, 2005). The health care system is in a prime position to identify women that might be experiencing gender-based violence (ARROWS, 2005) and, thus, be at risk for contracting HIV. In terms of health care, medical providers should screen for both gender-based violence and HIV. The health care community should view sexual violence, as well as other forms of violence against women, as a critical threat to women's health (Leone, et al., 2010). Furthermore, they must be trained to recognize the dynamics of intimate partner and sexual violence (Jewkes, et al., 2002) and be able to skillfully and sensitively discuss these issues with their patients (Anderson, et al., 2002). Finally, medical care providers need to be able to accurately assess risk for the transmission of STIs (Jewkes, et al., 2002) and ensure survivors of sexual assault receive treatment for common STIs (Hynes & Cardozo, 2000) and, if deemed appropriate, antiretroviral postexposure prophylaxis to prevent HIV infection.

Treatment

Provide "No Wrong Door" to Services

Once individuals contract HIV, there should be "no wrong door" to receiving comprehensive services, meaning HIV+ individuals should be allowed the freedom to define their own experiences and, thereby, seek services they determine best fit their needs. Hence, the numerous service providers with whom they come into contact, such as health care, mental health, rape/crisis, domestic violence and social service practitioners,

must to be able to provide respectful, customized care meeting their unique and multiple needs. As previously mentioned, domestic violence and sexual assault service providers must be trained to provide comprehensive information and targeted referrals to assist HIV+ individuals in accessing services. Although this research study did not have specific questions geared towards learning more about the women's experiences with the health care system, health care issues featured in each of the women's stories. In most cases, it was a health-related issue that first drew the individual to a medical provider who later determined their status. Their accounts of receiving treatment show that HIV+ African immigrant women not only have unique concerns but also share general health related concerns with other HIV+ women. Thus, we see that HIV+ individuals seeking services need to be able to obtain them from practitioners knowledgeable about the dynamics of gender-based violence, including sexual violence, and possibly provide survivors with options for counseling and assistance. This expanded knowledge base will enable service providers to provide integrated services (UNFPA, 2010) customized to the unique needs of each individual. This will require a holistic, multi-disciplinary approach necessitating extensive cross-training, program planning, and service collaboration (Weisman, 1997).

Develop Contextually-based Interventions

HIV treatment interventions are needed that address the reality of diverse women's lives, such as significant social, cultural and economic inequality (WHO, 2010). Previous psychological models have focused on individuals; their knowledge, attitudes and beliefs and their impact on behavior (Amaro, 1995). These models ignore the fact that

women face constrained decision-making when it comes to their sexual and reproductive health (Amaro, 1995; Rountree & Mulraney, 2010). Hence, female-centered approaches are needed (Amaro, et al., 2001). Rountree and Mulraney (2010) have conducted ground-breaking research on designing HIV risk reduction interventions for survivors of intimate partner violence that are contextually, as well as culturally grounded. They recommend that interventions for survivors of intimate partner violence should include sexual safety planning, among other strategies (Rountree & Mulraney, 2010). They also argue that in order to promote self-determination, effective HIV risk reduction interventions must "explore, educate and empower" when it comes to women's sexual health and decision-making (Rountree & Mulraney, 2010, p. 213). Furthermore, culturally appropriate interventions tailored to each target community are likely to be better received and, thus, more effective (Kerani, et al., 2008). HIV+ women themselves should be involved in the development of interventions designed to enhance their reproductive health and end violence against women (Rountree & Mulraney, 2010). Moreover, service providers must recognize the diversity of survivors from different backgrounds and communities (Sokoloff & Dupont, 2005) and include them in this process. This will lead to the provision of survivor-informed services for the prevention and treatment of HIV.

Offer Anonymous Services

The women in this study also recommended that service providers should offer HIV-related services in non-descript locations that do not expose the HIV status of individuals seeking services. This recommendation comes directly out of the women's experiences. During the interviews, the women described their anxiety in accessing

needed services for fear of having their status exposed. Mary shared a story of a woman in her home community whose status was exposed while receiving services in her home country and described knowing an individual who committed suicide after their HIV status was exposed. Based on the narratives of the women in this study, offering services in a facility easily associated with HIV, may deter some individuals from being tested or receiving services. Other studies of HIV+ African immigrant women living in the United States also found that women expressed fear of having their status exposed and requested anonymous testing (see Foley, 2005). Thus, it would be helpful if HIV service agencies did not have business signs with "HIV" or "AIDS" written on them. The afore-mentioned study also interviewed medical service providers and found that they had developed strategies to try to protect the identity and status of the individuals they served, such as providing medicine in unlabelled containers and delivering medications to alternative locations, as opposed to clients homes (Foley, 2005). In order to assist women who would not attend support groups because they wanted to maintain discretion, the study proposed a "buddy system" in which an individual is assigned to a client so only one trusted individual knows their status, as opposed to a whole group (Foley, 2005).

POLICY IMPLICATIONS

The findings from this study highlight the fact that in order to reduce women's risk for contracting HIV, gender-based violence and inequality must be reduced. Social policies and legislation, such as the Violence Against Women Act in the United States and legislation in South Africa making marital rape a criminal offense, can play a key role in this effort. Thus, it would be useful to conduct comparison studies among various nations

regarding legislation protecting women from violence, maintaining their reproductive health and holding perpetrators accountable.

In light of this study's finding regarding married women's vulnerability, these policies must include protections for married women, for example, prohibitions against marital rape. Unfortunately, at this time, marital rape is not a criminal offense in any of the nations represented in this study. Marriage laws in many countries are complicated by practices related to plural marriage that is a legitimate form of marriage in countries, such as Cameroon and Zambia. Regardless of whether plural marriage is commonly practiced in each country, policies should be put in place to ensure that wives have legal rights and fair recourse in terms of protecting their reproductive health and disease status.

Alimony and child support are other policy options that can promote women's financial independence and, thus, lower their risk for contracting HIV. Furthermore, laws regarding child welfare, sexual violence and intimate partner violence, are essential to keeping women safe. In addition, legislation against prostitution should take into account the fact that women may exchange sexual services to support the basic survival of their children and themselves. Also, although none of the women in this study identified as a member of the LGBT community, it is essential that members of the LGBT community are able to maintain their freedom and safety. Nations from throughout the world and Africa can look to nations, such as South Africa, which have enacted key legislation to protect women, as well as members of other vulnerable populations, such as the LGBT community. As virtually all societies are built upon a patriarchal system, thee policies mentioned above can be investigated to learn more about key contextual issues (in this

case policies) that either work to protect or endanger women. It would also draw attention to the similar or divergent path different nations have taken over the years in an effort to protect women.

Finally, it is important to note that policies are not gender-neutral documents (McPhail, 2003). Thus we must learn to think broadly in terms of the social policies and legislation that has a direct or indirect impact on women's reproductive health and disease status. Hence, individuals interested in promoting women's reproductive health and decreasing their risk of HIV should consider social policies that promote women's educational and economic opportunity, including equal pay.

RESEARCH IMPLICATIONS

Process of Future Research

This was a small exploratory qualitative research study. Thus, learning was generated by the process, as well as from the narratives that were collected. In terms of process, recommendations for future research are centered around culture, language and the study sample. I conducted this research as a white American-born woman for whom English is my first language. The women in the study were Black African-born women living in the United States for whom English is a second language. These differences have potential repercussions in terms of the women being able to identify with me and feel comfortable disclosing very personal information, such as incidences of rape. "Interpreter bias" could also potentially affect my ability to accurately understand and portray their narratives (Lopez, et al. 2008). Thus, it is important for academic institutions to support researchers from diverse backgrounds and nationalities. Ideally, future research

would be conducted by researchers from the same cultural and linguistic background, though admittedly that can also pose its own difficulties. It is possible, for example, that researchers from similar backgrounds may over identify with the women, or the women may not trust them to keep information confidential because of their affiliation with the community. Nonetheless, there are also important potential benefits, such as being able to better understand and represent the experiences of the research participants.

Due to the small size of this study and limited research funds, research participants were limited to English-speakers. This is a significant limitation, as it can be reasonably assumed that HIV+ immigrant women who do not speak conversational English may have different lived experiences and service needs than those who do. Therefore, future research should seek to give voice this hard-to-reach population of marginalized and highly vulnerable women. Furthermore, this study sought to learn from the experiences of immigrant women, including refugees. However, based on the organization's clientele and who was interested in participating in the study, no refugee women were recruited to the study. Future research should look at the experiences of refugee women who may have more to say about the role of migration in the structural and contextual factors facing women. It would be useful to compare and contrast the experiences of refugee women with those who migrated voluntarily. Putting diverse women at the center of analysis allows us to view phenomena from a different vantage point and, hence, promotes further learning. In conducting similar research in the future, researchers may find it useful to limit their study to one nation or community in order to mitigate the added complexity of having women from multiple nations and cultural

traditions. It is my hope that future research will show the diversity of African women and African immigrant women's experiences, and use the narratives and testimonies they collect in an effort to exhibit their strength, agency and power (Raphael, Taylor & McAndrew, 2008).

Content of Future Research

Research is continuing to shed light on the role of gender inequality and gender-based violence on women's risk for HIV. Recently, a sizable portion of this research is taking place in sub-Saharan Africa, mainly South Africa (see Jewkes, et al., 2001; Kalichman, et al., 2008; Madzimbalale, et al., 2012; Skinner, & Mfecane, 2004). Additional research on this topic should focus on the structural issues, such as poverty and migration, which have gendered impacts and contribute to women's risk for contracting HIV. Future research should also focus on better understanding the role of stigma and silence in the African and African immigrant communities. In researching how to overcome stigma and prevent the spread of HIV, future research should explore the role churches play in providing essential supports and/or reinforcing traditional gender roles and norms. Research on silence and disclosure should seek to determine whether not disclosing one's status leads to social isolation and delayed help seeking behavior. Additional studies interviewing service providers and community members could also be informative in improving prevention and treatment efforts. In addition, it would be useful to conduct research asking men their opinions about gender inequality, gender-based violence and risk for contracting HIV. Finally, much work is required in continued efforts to develop HIV prevention and treatment interventions that are

culturally sensitive and tailored to the diverse social contexts in which women live. This is essential because "…when education is culturally specific and tailored to the unique issues and needs of the targeted community, it is more likely to lead to positive outcomes" (Robinson, et al., 2002, p. 46). It is my hope that this research as to our collective knowledge-base on how to create culturally tailored interventions.

CONCLUSION

It has been said that "health occurs in the context of the daily experience – in the context of our collectivity, work, gender, environment, culture, relationships, politics, economics, social norms, history, faith and daily lives" (Pavlish, 2007, p. 34). The same complexity is true for women's reproductive health, including HIV status. Unfortunately, virtually all societies are based on patriarchal norms asserting male dominance and female submission (Strebel, et al., 2006) in a manner that promotes gender inequality and gender-based violence and puts women at risk for contracting HIV (WHO, 2010). Therefore, this exploratory qualitative study sought to examine the narratives of HIV+ women in order to develop strategies for overcoming gender inequality and gender-based violence in an effort to promote women's reproductive health and limit the spread of HIV. This study also sought to fill a gap in the scholarly literature by exploring the experiences African immigrant women a multiply marginalized population often ignored in research on reproductive health. The findings of this study demonstrated that by putting diverse women in the center of analysis we are able to develop strategies specific to their unique experiences, as well as enhance our understanding of the universal gender dynamics putting women at risk for contracting HIV.

Appendix A

Brief Demographic Information

Age:

Race/ethnicity/tribal affiliation:

Religion:

Native language:
Other languages spoken:

Country of origin:
Country of temporary settlement:
Length of stay in the US:
Immigration status:

Education:
Employment:

Sexual orientation:
Marital status:

Number of children:
Age of children:
Number of children with you in the US:
Members of extended family living in the US:

Location where received HIV status:
Date when received HIV status:
Length of contact with HIV service provider:

Semi-Structured Interview Schedule

I am interested in learning about family gender roles and decision-making. Can you tell me a story about growing up as a female in your family?

I am interested in learning about gender roles and decision-making within intimate partnerships. Can you tell me a story about your experience being a girlfriend/wife/mother?

I am interested in learning about how people make decisions within sexual relationships. Can you tell me a story about an intimate or sexual relationship you had, what decision was made and how that decision was made?

I'm also interested in hearing the stories women who may have been hurt by an intimate partner or hurt by someone in an intimate or sexual manner. If you have had an experience like that, would you feel comfortable telling me that story?

I am interested in learning more about women's views on how they may have contracted HIV. Can you tell me a story about a situation you feel may have contributed to you becoming HIV+?

Finally, I am interested in learning about your ideas on how to prevent the spread of HIV. When you think about your life, is there anything or anyone that you feel might have protected you from becoming HIV+?

Appendix B

Waiver of Consent

WAIVER OF DOCUMENTATION OF CONSENT

According to 45 CFR 46 Section 46.117, an IRB may waive the requirement for the investigator to obtain a signed consent form for some or all subjects if it finds either:

__ The research presents no more than minimal risk

AND

__ The research involves procedures that do not require written consent when performed outside of a research setting

45 CFR 46.117(c)(2)

OR

_X_ The principal risks are those associated with a breach of confidentiality concerning the subject's participation in the research

AND

_X_ The consent document is the only record linking the subject with the research.

45 CFR 46.117(c)(1)

IRB APPROVED ON: *EXPIRES ON:*

Appendix C

Oral Explanation of Research Study

Title: Perceptions of HIV Positive African Immigrant Women on Gender-Based Violence, Gender Inequality and Risk for HIV Infection

Introduction
You are being asked to participate in a research study. This form provides you with information about the study. In addition to reading this form, the principal investigator in charge of this study will describe the study to you. You can ask any questions you may have. Please read the information below and ask about anything you don't fully understand before deciding to participate in this study. Your participation is entirely voluntary, and you can refuse to participate without penalty or loss of benefits from the service agency, The University of Texas at Austin, or any other organization. We will not ask you to sign anything.

What is the purpose of this study?
You have been asked to participate in a research study to explore the relationship between gender-based violence, gender inequality and risk for HIV infection among HIV positive immigrants. The purpose of the study is to learn more about the lived experiences of women who are HIV positive in the hopes of gathering useful information on how to improve HIV prevention efforts.

What will you be asked to do?
If you agree to participate in the research study, you will be asked to:

- Participate in one interview with a researcher.
- The interview will be conducted in English, however, if it makes you more comfortable, you can request that an interpreter be present in order to ensure that you and the researcher are able to communicate easily with one another.
- Talk to the researcher about your experiences related to the topics of relationships, family, education, religion, sex, contraception, work, health, violence and HIV status.

Because the researcher wants to have an in-depth understanding of your experiences, the interview is expected to last approximately three to four hours. Over the course of the study, approximately five to twelve women will be interviewed.

This is a research study and, therefore, it is not intended to provide a medical or therapeutic diagnosis or treatment.

What are the possible risks to participating in this study?

There are minimal foreseeable psychological, physical, social or legal risks for participants. There could be a remote potential risk for exposure of participant HIV status. However, this study is taking multiple precautions to protect your privacy and confidentiality. Thus, these risks are very minimal and put participants at no greater risk than receiving services from the service agency. Potential risks may include an emotional response to the information you share with the researcher during your interview. If you feel discomfort at any point during the interview, you are free to stop the interview. You may also decide not to answer any questions. If you feel any distress or need further assistance as a result of this interview, you may contact the agency directly.

What are the possible benefits to participating in this study?
There are no benefits to you for participation in this study. Overall, the benefit of this study is a better understanding of the relationship between gender-based violence, gender inequality and risk for HIV infection.

Do you have to participate?
No, your participation is voluntary. You may decide not to participate at all or, if you start the study, you may withdraw at any time. Withdrawal or refusing to participate will not affect your relationship with the service agency, The University of Texas at Austin, or any other organization.

If you decide to participate, will it cost you anything?
No. It will not cost you anything to participate in this study.

Will you receive compensation for your participation?
Yes. You will be given $40 to compensate you for your time and expertise. Payment will occur at the beginning of the interview. You are free to stop the interview at any time, without the loss of this compensation.

How will your privacy and confidentiality be protected?
This study is confidential. You do not need to sign anything in order to participate. In order to arrange the interview, a service agency staff member will give the researcher your first name, however, you can also choose to use a pseudonym. If you would like, you may provide the researcher with a phone number in order to facilitate arranging the interview. If you would prefer not to, you can plan a time and location for the interview without the use of a phone. If you chose to give the researcher your first name and/or phone number, that information will be destroyed after your interview.

With your permission, the interview will be audio-recorded. Your privacy and identity will be protected, and no personally identifying information will be visible on the tapes. The interview will be transcribed, and no personally identifying information will be included in the transcription or in any report of the study findings. Tapes will be heard or viewed only for research purposes by the investigator and her associates. If the results of this study are published or presented at an academic conference, your identity will not be

revealed and your voice will not be used. The recording will be secure and remain in a locked location. The recording will be destroyed after it is transcribed.

How can you remove yourself from this study and who can you call if you have questions?
If you wish to stop your participation in this research study for any reason, you should contact: Joy Learman, Principal Investigator. Ms. Learman can be reached at 713-899-1995 or jlearman@utexas.edu. You can also ask her any questions you have regarding the study prior, during or after your participation.

This study has been reviewed and approved by The University of Texas at Austin's Institutional Review Board and the study number is 2012-01-0124.

Who should you contact with questions about your rights as a research participant?
For questions about your rights or any dissatisfaction with any part of this study, you can contact, anonymously if you wish, the Institutional Review Board for the Protection of Human Subjects by phone at 521-232-2685, or the Office of Research Support at 512-471-8871 or by email at orsc@uts.cc.utexas.edu.

You have been informed about this study's purpose, procedures, possible benefits and risks. Do you have any questions? Are you willing to participate in this study?

Before the interview starts, the researcher asks, "are you willing to participate in this study? Is it okay with you if I tape this session?" If yes, it will be recorded. If no, the researcher will take notes.

Appendix D

Life Histories

Introduction to Life Histories

The six women who participated in the study are named: Brenda Lynn, Kiza, Liz, Marica, Mary, Michelle. Each of their names were changed for the purposes here in order to maintain their confidentiality. Brenda Lynn, Kiza, Liz, and Mary all believe they contracted HIV through heterosexual intercourse. Their narratives highlighted issues related to gender-based violence and gender inequality. With the possible exception of one of these women, who may have been infected while engaging in survival sex, they all believe they contracted HIV from their husband/live-in partner. Marcia and Michelle's stories provide an interesting counter narrative as they were both infected as children. Michelle was infected through a blood transfusion and it is not known how Marcia was infected. Both Marcia and Michelle married HIV- men and are in the process of starting their families while working to ensure their husband's HIV status remains negative. Their narratives highlight issues related to sexual decision-making and mixed status relationships.

Statement on Confidentiality

Due to the urgent need to maintain the strict confidentiality of the women who participated in this study, many of the personal details could not be included in the life histories for fear of inadvertently revealing an individual's identity. Therefore, I have

sought to omit all identifying information. For example, listing the number of children a woman has, or including a medical diagnosis, might be relevant to her life history, but may also contain revealing information about her identity. Although I would like readers to get a strong sense of each woman and her unique life circumstances, I realize that offering a cohesive story about each woman could put them in danger. Thus I have decided to take these precautions because their safety and confidentiality is my top priority. This is especially important due to the potentially dire consequences of having their status exposed, such as being exposed to stigma, social isolation and even violence.

Brenda Lynn. After a long and fruitful marriage, Brenda Lynn became estranged from her husband in her home country. Despite the intervention of friends and neighbors, he refused to share his salary for the support of their children. Fearful of having more children, she began to refuse having sex with him. The last six months of their marriage was punctuated by almost daily incidences of sexual assault against her. In an effort to help her escape this dangerous situation, a friend from her home community who lives in the United States invited her to stay with her for "a rest". Brenda Lynn explained: "I didn't want to leave my kids. I didn't want to let them suffer…But it came to the point when this friend asked me, 'It's too much. You can come here and have a rest.' I decided to come." After living in the United States for a few years, she went to an emergency room because she was feeling ill. There she was tested and found out she was HIV+.

Brenda Lynn believes she most likely contracted HIV from her husband who had many sexual partners during their long marriage. There is a smaller chance (due to fewer

exposures) that she contracted HIV while engaging in survival sex with men from her community in order to support her children after becoming estranged from her husband. Brenda Lynn became very animated when talking about her reaction to learning of her status. She said:

> I started crying because I didn't know what to do. I knew in my mind I was going to die because back home women don't have the money to buy medication. The nurse told me 'Don't cry we will help you look for a way to have the medication.'

Kiza. Kiza is from a very successful and powerful family in her home country. She followed a relative to the United States and has lived here for many years. While in the United States, she has focused her time and energy on her education and career. She is currently married to someone from her home country who she sponsored to come to the United States.

When her husband was completing the paperwork to come to the United States, he had to be tested for HIV. He tested positive. Following the receipt of his results, Kiza was also tested. Because she already had a recent baseline test, she is confident that she contracted HIV from her husband as she didn't have any other sexual partners. After learning of her status and being told she needed to see a doctor, she explained: "I didn't know where to start. I didn't know where to go. There was nobody to ask, and then it was something that you don't want to ask just anybody." She confided her fear in a case manager and her case manager reassured her saying: "These days they have medicines. It's not like...you know, you're gonna die. It's not a life sentence. You need to be strong."

Kiza responded by stating: “I cannot tell my family this. I cannot do this.” After learning of her husband’s status and wondering if he already knew it prior to marrying her, she briefly considered not completing the paperwork to bring him to the United States. But in the end, she decided to do it in an effort to get him treated and reduce the risk of him spreading the virus to someone else. She also decided not to blame her husband instead wanting to look to the future because, in her words, “it was not going to make any difference” as she was already positive.

Liz. After leaving a history of sexual victimization and her first long-term relationship in her home country, Liz moved to the United States and married an American-born citizen. She experienced severe physical violence by her husband who became addicted to drugs. After sustaining serious injuries and becoming concerned for the safety of her children, she moved into a domestic violence shelter where she underwent counseling. She now has a new relationship and is open about her status with her church and community members. Liz believes she was infected during a long-term relationship with a previous partner in her home country. He started traveling to other countries for work and she believes he had multiple concurrent sexual partners.

Liz learned of her HIV status when one of her children was sick. She took her child to the doctor and they tested positive for HIV. She was then tested and found out that she was also positive. Of learning of her status, she said: “I was so scared and I didn’t know what to do.” In terms of coping with the virus, she said: “My kids, they keep me going, and we just, accepting that, you know, I have this virus and I can keep on

living as long as I take my meds." When asked about how she grew personally in terms of being comfortable with her status, as well as overcoming her history of violent victimization, she said "Through education, learning more about the illness. Before I used to think I was going to die like right away…I am taking my medicines every day, I am eating right, I am exercising, and I am feeling better every day."

Marcia. Marcia worked in the medical field in her home country, a place that is no stranger to war. Marcia moved to the United States in order to join her husband, a native of her home country who had previously moved to the United States. She hopes to eventually pursue a medical career in the United States.

Marcia contracted HIV as a child and to this day does not know how it was transmitted. Her only guess was that she contracted it from a female family friend she had lived with as a child. The true cause is unknown as this scenario is unlikely because HIV is not transmitted through casual contact. Marcia was tested for HIV as a teenager during treatment for another health issue. The doctor revealed her status to her mother and a male relative. Her mother had no idea how she was infected and never told Marcia of her status. Marcia first became aware of her status when the trusted male relative (the only one who knew besides her mother) told her after she announced that she was engaged to be married. He said: "You have to stop. You are HIV+. There's no way you can." Initially, Marcia did not believe her relative. But was tested again and received her results. She said: "It was very hard." After discussing the situation with her then fiancé, they decided to proceed forward with getting married and starting a family together.

Mary. Mary has experienced the horrors of war. Her husband was arrested and killed during political upheaval in her home country. She was subsequently arrested herself and feared for her life. A family member was able to intervene on her behalf and help her escape to a country of temporary resettlement. From there, she was finally able to enter the United States and is in the process of applying for asylum. While working here in the United States, Mary was injured and was taken to a hospital for treatment. During the visit, she tested positive for HIV.

She said she is "80%" positive that she was infected by her husband, since he was her only sexual partner. Her only reluctance to definitively say that she contracted the virus from him stems from the fact that he appeared so strong and healthy to her. So, it is hard for her to reconcile that he might have been HIV+. Mary stated that finding out she was HIV+ was a "disaster" for her and that she cried for almost a month. She described it thus:

> Since that day I found out, it was very, very, very hard. Very hard. Like I told you, Africa is where they tell you about HIV. You see yourself like you are going to die the next day. I'm Christian. I have fear for my God. I don't have boyfriend. I don't never have sex. Never, never beside my marriage.

Michelle. Michelle is a student, a newlywed and an athlete. She is pursuing her education to become a medical professional in order to help others. She followed her parents to the United States as a child. Her parents came to the United States to obtain their graduate education. After about a year of living in the United States, Michelle

became very ill. Her parents sought medical attention for her and through the course of testing, found out that Michelle is HIV+. She described the day she found out about her diagnosis thus:

> So, we went to (the hospital) and the doctor like… no, I could see the seriousness. I was such a young age, I don't know how I could notice that. I could see all the seriousness. And the doctor told my mom, 'Your daughter has HIV.'…. So (pause)… the doctor was trying to reassuring me 'Everything is going to be fine. We're going to start medicine. Don't worry.'

As a middle schooler, Michelle did not have any risk factors for contracting HIV. No one else in Michelle's immediate family was infected. Through the process of elimination, Michelle's family believes she became infected as a child when she received a blood transfusion at an early age. Of being diagnosed, Michelle stated: "I was diagnosed like a year after I came here…So, like, it was hard enough already. I didn't have anybody."

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